Towards a more ordinary life….

A report on the progress of parent carer participation and the development of short breaks: 2008 - 2011

Contents Page

Foreword

All children and young people have the right to live safe, happy and productive lives and should be given fair access to opportunities that help them to grow and develop, enjoy and achieve, support to become independent, fulfil their potential, and take their place in society as citizens. Being disabled should not create barriers that prevent these things, but we know that for many years disabled children and young people, and their families have faced significant challenges and lack of access to services that ultimately impedes these life opportunities. Many disabled children have not had the opportunity to experience activities that non disabled children take for granted – going on holiday with school, sleeping over at a friend‟s house – having the chance to make friends, and undertake activities without their parents being with them. Many ordinary life situations have been difficult and sometimes impossible for some children to experience.

Yet these are the very situations that enable families to have time away from each other to develop as individuals. Parents of disabled children especially need time away from the responsibility of caring to enable them to have a break so that they can manage the day-to-day demands of supporting their children. For too many years, the lack of regular short breaks was cited as the „biggest single cause of unhappiness‟.

Parents of disabled children also talked of „battling‟ with authorities simply to try and secure services that should often have been theirs by right. They felt disempowered by the way services were distributed, perceiving themselves to have no voice or say in the way that services that their children, and they received and experienced were developed, and purchased, or in reviewing if they were satisfactory, and met the needs of their children.

Over the last three years there has been a concerted effort made to address these issues in the form of the national service development programme „Aiming High for Disabled Children‟. Substantial financial resource was made available to local authorities and their partnering primary care trusts to significantly increase and improve the volume and range of short breaks for disabled children and their families. Alongside this, investment has been made to develop and strengthen the participation of parent carers in the planning and evaluation of all disabled children‟s services. *Together for Disabled Children* was the delivery partner to the Department for Education for this programme and this report tells the story of the transformation that has been seen across all local areas in England.

Significant headway has been made, with some very exciting developments being seen, and parents in every part of the country are now able to link into structures at a local level that will help them make their voices heard. A National Network of Parent Carer Forums has been developed that will enable the collective voice of parents to have an influence in shaping services in the future.

Short breaks have increased, the range of choices has grown, with some wonderfully innovative models being evidenced, and over 100,000 more children have been able to access services. This is a fantastic achievement and officers involved should be proud. Disabled children are engaging in fun activities that also enable their parents to have a break and opportunities for learning and socialising have increased. The „ordinary life‟ is becoming more accessible.

It is acknowledged, however, that this is only the start and services still need to grow; further work needs to be done to ensure lasting change. But there is much to celebrate, and we should do that. So we commend this report to local authorities and their partners, as well as to parent carers of disabled children and to voluntary and community sector organisations.

By seeing how much has been possible to achieve, in such a short period of time, and with the examples given of many models of service that demonstrate cost-effective solutions, we hope that authorities will be encouraged to continue with their own plans for commissioning of short breaks with renewed momentum. We especially trust that they will come to understand that working in partnership with parents, with disabled children and young people – putting them at the heart of service development – and that effective working relationships with other organisations is essential to transforming services and achieving the best possible outcomes for all.

From April of this year, local authorities have been under a duty to provide short breaks services to carers of disabled children[1]. These regulations build on the rapid expansion that has been seen through this programme and are evidenced in this report. Over £800 million of funding has been provided through the Early Intervention Grant to continue developing short breaks services and grants and continued direct support from the Department for Education has been committed to parent carer forums over the next five years to enable them to be further strengthened.

The Department for Education continue to actively promote and support these developments for services for disabled children. There is still a journey to complete and the vision is ambitious amidst a period of great challenges. However, to achieve better life chances for disabled children and young people and their families – those that face some of the greatest barriers and challenges in our society - it is essential that local areas do not see this as the end of the programme of transformation of services for disabled children, but rather that this has been the start. The Department for Education are committed to continuing to work with local areas and providing support to enable the vision to be taken forward, but the reality of this will only be achieved if the passion, enthusiasm and drive that has seen the remarkable transformation over the last three years continues. With parent carers, local authorities, health partners and the voluntary and community sector working together, there really can be an embedding of the transformation, and continued developments to ensure that disabled children and young people have the opportunities that they should – to lead full and active lives, and provided with the appropriate support to do so to ensure that every child fulfils their potential.

Signed

Rita Wiseman B Playle

Rita Wiseman	Bev Playle
Director of Strategy and Stakeholder Engagement	Director of Operations

Executive Summary

This report was commissioned by the Department for Education and produced by Together for Disabled Children – a partnership formed between Contact a Family and Serco Plc to deliver on the development of parent carer participation and short breaks services. These were central components of the Aiming High for Disabled Children programme which ran from 2008 to 2011.

The Government invested substantial financial resources and made available over £270 million to local authorities, with significant additional funding in the baselines of PCTs, over a period of three years, to enable them to significantly increase the volume and range of short breaks provision. It also allocated grants to all local areas to enable to them to develop and strengthen mechanisms and forums for parent participation. In April 2011, new legislation, in the form of the Short Breaks Duty came into place and, as a result, all authorities are required to publish a short breaks statement, detailing the provision available and their entitlement frameworks. Many authorities are in a position to be able to fulfil these legal requirements, yet others will find it more challenging.

The progress made in the past three years has been immense. Many areas started from a baseline of severely limited services, with no lead officer in post to take forward a change programme and no history of working in partnership with parents and carers. Disabled children‟s services have often been referred to as a „Cinderella‟ service, with the perception that it was underfunded and afforded low status. This unfortunate perception became self-perpetuating and staff often found themselves feeling demoralised and in conflict with parents, due to having to ration a very small resource pot, when they were the very people they were aiming to support. Parents themselves reported that being exhausted from caring as well feeling powerless led to them being forced into an embattled position. Outcomes for disabled children were not good, with many being denied access to ordinary life opportunities.

Aiming High has transformed the picture that was painted in 2007. There is no denying that the journey is incomplete; there is still a long way to go. The immense changes and the work that has been needed to bring these about need to be acknowledged. There is much to be learned from reflecting on the journey so far, which will provide an impetus for continued change and the securing of firmer, long-lasting services in the coming years. Journeys across the country have varied: each locality had a different starting point and has its own strengths and challenges. However, no area has stood still and there have been some brilliant examples of passionate commitment, collaboration and innovation. Indeed, these three themes have become key features of the whole programme.

Passionate commitment – few streams of work seem to engender such an abundance of passion than anything concerned with disabled children. It is almost as though all involved have waited so long they know they cannot waste any time. The effort put in by parents, professionals and managers alike to see this programme have an impact has been immense. The challenges at the outset were great – paucity of data, lack of capacity, limited capability, weak structures and low priority – to name but a few. However, the number of officers who have „gone the extra mile‟ to make sure that services were really transformed has been inspirational to see.

Collaboration – more innovation was seen where there was collaborative working with parents and also with other organisations. Local authorities that invested time and energy into developing partnerships with health sector services and voluntary and community sector organisations have seen this pay dividends. The development and strengthening of relationships seems to be key to achieving better outcomes.

Innovation – the additional funding enabled areas to take some risks and to try and „do things differently‟. The greatest successes have come about from starting with the outcomes that children and families wanted to see achieved and working backwards from there. This has led, in many cases, to a radically different way of commissioning services and a much greater involvement, at all levels, of parents, children and young people themselves. Local authorities report that they have amazed themselves and are committed to making sure that the transformed approaches are here to stay.

As one local authority lead officer said, “There‟s no going back now – we‟ve come too far. This is how we do things round here now.”

This report tells the story of the transformation. Beginning with parent carers, it details the growth of forums and the increase in the number of parents involved. It tracks the development of regional and national structures that have strengthened the voice of parents and enable them to actively participate in shaping policy planning and services in the future.

In the second section, it tells the story of the growth in volume and range of short breaks services. It gives the detail underneath the statistics of 105,000 additional children who are now receiving short breaks and the extra 193,000 nights and the eight million extra hours each year that are being delivered. It discusses the way that services have been developed for children with the severest level of needs, who often previously received the least help, and explores the way that authorities have grasped the concept of personalisation to deliver more than 20,000 direct payments and 3,000 individual budgets.

It also tells of the growth in commissioning from the voluntary sector and the role of that sector in creating innovative responses to need. Throughout the report, there are numerous brief examples that are there to inspire and to make people think. In most instances we have provided the local authority or organisation‟s names so that the reader can follow up if more information is needed.
Finally, it looks at the factors that appear to have enabled successful transformation across the areas that have achieved the best outcomes and discusses the steps for going forward and ensuring lasting change.

Key headlines

Parent carer participation

- Structures to facilitate consultation with parent carers have been established in all local areas and parent carer forums to enable participation have been developed in almost all local authority areas
- Effective parent carer participation has had a positive influence on commissioning practices, leading to increased value for money in service provision
- The number of parent carers actively involved in strategic planning of services in their own localities has increased to 1,710 parent carers across 146 local authority areas, up from 465 in September 2008
- 96% of local areas report that there is evidence of improved working between parents and professionals
- The development of Regional Networks has enabled local forums to share experience and expertise which has supported and embedded parent carer forums
- A National Network of Parent Carer Forums has been established to coordinate the engagement of parent carers in policy shaping and planning, and it is developing credibility as a collective, influencing voice for parents
- Parent carer forums are involving parents that have been harder to reach and three pilot projects have been successful in increasing participation of parent carers from black and minority ethnic (BME) groups
- Local information for families of disabled children is better coordinated
- More than 8,000 parents have been involved in training of some sort to support better parental engagement
- Involvement in participation has increased the confidence of parents, improving self-esteem, leading to a range of improved outcomes for parents

Short breaks

- Over 105,000 more disabled children are receiving short breaks – an increase of 184% since 2008
- Over 73,000 more children with the severest level of needs are now receiving short breaks – an increase of over 200%
- Reach – the proportion of disabled children receiving short breaks as a percentage of the total child population – has increased to 1.36%
- Significant growth in the volume of short breaks provision has been demonstrated. An additional 193,000 nights (an increase of 33%) and an additional eight million daytime short break hours (an increase of 135%) are now being provided each year
- Increased engagement of parents in the commissioning process and a greater level of partnership working with providers has led to services being developed that are giving better value for money - more services are being delivered to more children at lower unit cost
- The shape of market provision is changing significantly in response to the expressed needs of children and families and more „ordinary life‟ models of provision in universal settings have developed - giving excellent value for money as they are easier to access and give high user satisfaction
- Personalisation of short breaks is being seen in service development, with a demonstrable commitment to active participation of disabled children and their families. 20,000 children are receiving a direct payment as part of their short breaks package (an increase of 83%) and almost 3,000 families are in receipt of some form of individual budget (an increase of 184%)
- Collaborative approaches and more effective relationships between local authorities and voluntary and community sector organisations have been key to

the transformation of commissioning practice and the development of the local authority‟s role as market manager

- The voluntary and community sector has played a key role in shaping service development, delivering innovative models of service provision, supporting development of a diverse workforce and working to support parents/carers and young people to have a more influential voice in how short breaks are commissioned and delivered
- Local authorities are seeing 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
- Children and young people are taking a more active role in shaping services and the programme has been a catalyst for change in increasing children‟s participation

Introduction

This report has been produced to mark the end of an intensive three year programme, Aiming High for Disabled Children (AHDC), funded by Government to rapidly increase and improve services for disabled children and young people and their families. The AHDC programme followed a series of Parliamentary Hearings on Services for Disabled Children in 2006 which highlighted the struggle faced by many families with disabled children to access the most basic level of services and support

As part of this wider programme of change, the Department for Education (DfE)[2] commissioned „Together for Disabled Children" (TDC), a partnership formed between Contact a Family and Serco, to be its delivery partner in supporting local authorities and their partners to implement two of the AHDC elements: „increasing and improving parent participation through the development of parent carer forums" and the „development of short breaks services."

This report summarises the improvements that AHDC programme has brought about over three years, and highlights the challenges local authorities, parents" forums and the organisations involving in supporting disabled children and delivering services will face in the future.

Contextual information

Support for implementation

TDC was commissioned to provide a programme of assistance for local areas to enable them to achieve the required step-change in order to strengthen or develop parent carer participation and significantly increase the range and volume of short breaks in every local area.

Support for the development of parent participation and parent forums

Parent participation advisers were based in each region and provided named contact points for the parent carer forums in the region, as well as being facilitators of regional events. Support was given to develop parent carer forums and to strengthen existing groups. Participation advisers promoted consultation as well as involvement and empowerment of parents. Joint workshops with parents and local authority officers were facilitated to enable mutual understanding and enhance relationships. An essential element of the role was to support groups to apply for the available grants, setting clear objectives and developing plans to increase participation.

Subsequently, expenditure against agreed outcomes was monitored. The growth of parent participation from the parent forums‟ perspective, as well as the local authorities‟, was measured through a web-based tracker system for local authorities and questions from the forums. Additional workstreams included the development of regional networks, the National Network of Parent Carer Forums (NNPCF) and specific work around promoting the participation of black and minority ethnic parent carers. A community leadership programme was developed in the final year resulting in courses being offered to parents covering some of the main principles of working in and leading groups.

Parent participation – assessing development and growth

Parent carer forums were assessed against their development and growth using a high/medium/low support rating process to determine the level of support required to progress. Supplementary data from the forums has also provided a national picture of progress and development. Completed annually and included within the grant monitoring forms, this provides data about a range of issues, including how many parent carers are involved in strategic decision-making groups and how many parent carers are linked with each forum.

Support for the transformation of short breaks

Starting with a comprehensive needs-based assessment, areas were offered a menu of support contingent on their identified level of need. All areas received access to regional events, cluster group workshops, action learning[3] sets, and to the web-based information portal. Each area also had a central point of contact for the duration of the programme, usually based in the region.

Areas had access to a named local programme adviser who offered an agreed number of support days to that local area, depending on assessed support needs. Advisers would usually have face-to-face contact meetings with the areas they were allocated to support every quarter and in some cases, where support needs were high, would visit up to eight times each quarter. Advisers challenged as well as supported, this being an effective strategy to encourage areas to reflect on decisions made, actions being taken, the direction of travel and their overall progress. Advisers also worked with areas to enable them to compile evidence of their progress and to be able to demonstrate that they had achieved particular elements of the Full Service Offer (FSO). The challenge element of the adviser role was essential in maintaining momentum, providing a positive steer for the programme and in driving quality.

Short breaks - Full Service Offer

The Full Service Offer (FSO) was set out explicitly in the Short Breaks Implementation Guidance[4]. Ten elements had to be achieved by local areas, which would essentially demonstrate that a comprehensive short breaks service was being offered to families in each locality. These elements were linked to the four objectives of the short breaks development programme (see appendix II - How programme objectives link to the Full Service Offer (FSO).

Programme objectives:

1. To develop short breaks services that are based on a comprehensive local assessment incorporating the views of disabled children and young people and their parent carers.
2. To significantly increase the volume and range of short breaks available to disabled children and their families.
3. To significantly improve access to short breaks services and to ensure that there is clarity about how services can be accessed and how they are provided.
4. To improve the quality of short breaks and ensure that they are a positive experience for disabled children and young people and their families.

The four objectives were further broken down into four stages that built upon each other and were to be achieved at intervals over the three years of the programme; the final stages to be achieved by March 2011. Local areas were able to track their progress on the web-based portal, which also enabled TDC to monitor the number of areas that had achieved the stages of each programme objective at any given date.

In order to progress through each stage, local areas were required to supply evidence to demonstrate that they had achieved all the agreed indicators for the stage. The indicators were agreed by a group of local authorities working with TDC and the DfE at the beginning of the programme and culminated in the Staged Progression Framework that also gave guidance to areas on the types of evidence that could be used.

Pathfinders

21 pathfinders were selected by the DfE, chosen to represent a range of authorities, including urban, rural, unitary and county councils, as well as being at different starting points. They were charged with generating learning and best practice that

could inform developments and practice in other local areas as funding became available to every local authority. The pathfinders were allocated their funding ahead of others and received additional money to help them achieve the FSO a year earlier than other areas.

Achievement of the Full Service Offer

Of the 21 pathfinders, 19 achieved the FSO by the agreed date of 31st March 2010. The two remaining pathfinder areas received additional support and achieved all remaining stages by September 2010.

Of the remaining 131 areas, 129 achieved FSO by 31st March 2011. As at 31st May, there remain two areas that have not yet achieved all the milestones of full service offer. However, TDC has continued to support and assist these areas to devise a structured plan for achieving by September 2011.

Data collection and reporting for short breaks

A key factor in maintaining the momentum for driving forward transformation has been the requirement for local areas to provide evidence of improvement and growth. Every quarter, each local area was requested to submit a planning and implementation report that detailed baseline figures on service provision and finances, and also projected future provision numbers and how revenue and capital would be used to achieve this growth. This tool became known as the LAIMP (Local Area Implementation Plan) and had to be updated at each return with details of actual number of children receiving services that quarter, the number of nights and hours provided and a revision of projections going forward. Achieving this level of planning was a major challenge for all areas. Data on disabled children was sparse and most short breaks lead officers had little access to support for data collection at the outset. Improving data collection and reporting was therefore a priority for TDC. Data has improved hugely over the course of the programme and is far more reliable. This will be a key factor in supporting areas with their sustainability planning as areas are far better informed as commissioners and better able to articulate the case for continued investment in short breaks. The data submitted by local areas in their LAIMPs has been used in the preparation of this final report.

Progress reviews/quarterly questions

TDC also asked a number of qualitative questions of local areas each quarter to help understand how they were going about the task of development. Two formal progress review exercises were carried out in June and December 2010. The second of these were facilitated self-assessments and local authorities were strongly encouraged to ensure that parent carers were part of these reviews, in addition to other local stakeholders. Parents were present at all but 34 of the progress reviews and in most of these 34 areas other ways for parents to be involved and to contribute were established. The process enabled local areas to reflect on their own journey, celebrate successes, share responsibility for progress not made and make decisions about moving forward. The responses from the quarterly questionnaires and from the progress reviews have been used to inform this final report.

Achievements

A number of local areas have „stood out from the crowd‟ in terms of the progress they have made. Some of these areas were pathfinders but there were others too that demonstrated outstanding progress from which best practice can be drawn. Not every area has excelled in every aspect; there are those that have achieved positive outcomes in short breaks in universal services but that have not been so good at developing family-based models of provision, for example. TDC has used a variety of measures to identify those areas that have made greater progress in particular areas (including analysis of reported quantitative data). We have facilitated focus groups, carried out telephone interviews and administered questionnaires in our efforts to capture the learning and disseminate helpful learning points to others. The themes generated from this methodology have also been incorporated in the relevant sections of this final report.

Short breaks evaluation study

As a parallel piece of work, a study to evaluate how pathfinder sites had gone about commissioning and providing new short breaks was undertaken by the National Development Team for Inclusion[5]. This was carried out in late 2009 and early 2010 and used a „realistic evaluation" approach. From the study, seven „theories of change" were identified to help explain the changes in pathfinder sites:

1. **Parent participation** – investment in a range of strategies to involve parents as full partners in co-production results in improved outcomes and innovative short breaks
2. **Imprecise nature of short breaks** – lack of national clarity of the definition of short breaks was a double-edged sword – stimulating creativity in some places and situations and hindering it in others
3. **Inclusion and ordinariness** – increased focus on the use of community settings increased inclusion, but many short breaks in inclusive settings remain segregated in nature - parental wishes were a driving factor in development of this style of provision
4. **Commissioning for innovation and change** – a wider range of short breaks reflecting choice is being developed where commissioning processes are being flexibly applied
5. **Partnership working** – strong partnership working leads to significantly improved services and outcomes
6. **Access and equity** – new „easy access" methods have broadened access for young people with less complex needs, with some progress being made for children with more complex needs. However, significant variation on access still remains and this is linked to factors such as information provision
7. **Importance of accountability and resource protection** – identification of national funding and the requirement to report on its usage and general progress have directly assisted the delivery of policy at a local level

Two further theories were identified where evidence was less strong:

8. **Participation of children and young people** – involving young people in service design, development and evaluation is leading to more accessible and child-focused short breaks
9. **Sustainability and a lasting legacy** – engagement of mainstream services is raising the profile of disabled children and helping to create a culture that has the potential to achieve long-lasting inclusion

These theories of change concur largely with the findings of TDC from our work with local areas. In the later section of this report, „Factors contributing to successful transformation‟ we set out some of the factors that local areas consider have helped them to achieve positive outcomes.

Section 1:

Parent carer participation – a lasting legacy

Developing and strengthening parent carer participation in the shaping of policy and service provision for disabled children and young people

Supporting the development of parent carer participation

Headlines

- Structures to facilitate consultation with parent carers have been established in all local areas and parent carer forums to enable participation have been developed in almost all local authority areas
- More parent carers are actively involved in strategic planning – 1,710 at March 2011 across 146 areas, up from 465 in September 2008
- 99% of local areas have seen an increase in the number of parent carers involved in participation
- 96% of local areas report that there is evidence of improved working between parents and professionals

Chair of a parent carer forum

"You can go to a group to be supported, but the forum is the place to go where you feel empowered and have a say in the City Council."

Starting point

Evidence[6] tells us that where parents are „active agents‟ rather than „passive recipients‟, in terms of service provision, more positive outcomes for both parents and children can be achieved and this includes, significantly, the lowering of stress levels, increased feelings of control over their child‟s wellbeing, better use of services and increased parental understanding of how services work. This results in better working relationships with professionals.

At the start of the programme, there were some existing examples of parent participation and involvement in a few local areas across the country at the outset of the programme. The efficacy of these forums demonstrated a range of benefits and led to the working principles underpinning the parent participation element of AHDC. However, these examples were not widespread and the pervading theme was one of parents feeling, at best, excluded from having any meaningful dialogue with service commissioners and at worst, as if they were „battling‟ with authorities or being „fobbed off‟ with a service that did not really meet their needs. Parents reported feeling frustrated that there were limited ways to feedback their experiences to those responsible for commissioning as only a few areas had structures in place to link parents‟ groups into service planning and decision-making.

Defining parent carer participation

The purpose of participation is to ensure better outcomes for families of disabled children and to improve services for all users. It is about the involvement of parents with a wide range of professionals and local service managers in the planning stages of service delivery. It is underpinned by the following principles:

1. User involvement should be central to policy making, and the design and delivery of services at a local, regional and national level
2. Parent carer participation is acknowledged as mutually beneficial to service planners and service users
3. Parent carer participation currently still needs support both financially and developmentally at a national, regional and local level
4. Local authorities will continue to consult with and involve parent carers in service development and delivery

Three key elements for effective parent participation are:

1. **Information** – providing information to parents about service development and their opportunities to influence.

2. **Consultation** – getting feedback from parents about their experience of services to inform further development, and offering options about a new service or a change in services, usually on a limited range of choices.

3. **Participation** – giving parents a significant voice in the design of a new service and the development of a service over time.

Developing parent participation

Grants of £3,300 in the first year and £10,000 in each subsequent year were made available to local areas to develop a forum or strengthen an existing one. The starting point for developing parent carer forums across the country varied with some areas already having parent carer forums working with services and others with no history of parent participation. At the beginning of the programme, each area was assessed to determine the level of support that it needed and this was reviewed quarterly.

The range of support from TDC included the following:

- Named advisers in each region to advise and support with the development of the forum
- The distribution and monitoring of the parent participation grant
- Facilitation of regional networks of parent carer forums
- Arrangement of joint regional events for parent and children service leads about participation
- Mediation in areas where differing views was blocking progress
- Development of guides, toolkits and sharing of good practice

The goal was to establish a parent carer forum or participation structure in all local areas open to all parents of disabled children that was recognised and linked into a range of multi-agency services as the established mechanism for gaining the views, involvement and participation of parent carers. At the beginning of the programme very few local areas had parent carer forums that met these criteria.

Where there was no established forum, parent groups or local carers‟ voluntary organisations or Parent Partnership Services applied for the grant and led the work. In a few areas the local authority was both the lead and grant holder.

Forums developed different structures to facilitate parent participation, which reflected the specific needs of the areas. A variety of activities were organised by the grant recipients to engage parents with the local authorities so that they could express views and contribute to how services would develop.

As they became established, parent carer forums used the grant to develop promotional material and communications to keep parents informed, created websites and provided training to parents actively involved or wanting to get involved. The grant was also used to pay for costs of meetings of forum steering groups (venue, parents travel, childcare) as well as to fund open meetings for parents of disabled children.

Parent carer forums wanted to reach a wider range of parent carers and used a variety of methods to achieve this. Some forums attracted new parents by running workshops and consultations around specific issues. Others found combining a consultation with a fun family event was effective in reaching parents not already involved, including families from hard to reach groups. Some parent carer forums ran events specifically aimed at reaching particular groups.

Progress of parent participation

Headlines:

The majority of local parent carer forums report that:

- They are reaching a wider range of parents and that parents who have been historically harder to reach are now more involved
- There is improved joint working between parents and professionals
- Local information for families of disabled children is better coordinated
- Parent carers in most areas have been trained in participation methods and new resources and tools for parent participation/involvement have been developed

Parent contacts

The grant holders were asked about the number of parents for whom they had contact details, the number on their database or the number asking to be kept informed about participation. This provides an indicator of the number of parents being informed about opportunities to participate. 77% of parent carer forums report that they are in touch with over 100 parents (in their own locality) and are better able to represent a range of parent carer experiences.

Parents active in the development of local parent participation

Grant recipients reported on the number of parents involved in running the parent participation work/forum. This refers to the number of parents who are involved in developing and coordinating parent participation for the area and encouraging other parents to get involved. At the outset, 35% of areas had no parents actively involved in running a forum and only 29% of areas had more than five parents actively involved. By the end of March 2011 only one area had no parents involved and 84% of areas have more than five parents actively involved in running the forum.

Parent representatives

Parent forums have representation on a variety of boards responsible for service planning, decision-making and monitoring the implementation of local strategies. They have participated in commissioning processes at various levels.

The total reported number of parents involved in service planning groups, across all areas, has increased from 465 in 2008 to 1,710 in 2011.

Parents receiving training

A total of 4,704 parents in 137 local areas received training in 2011.This was almost double the number of parents receiving training in the previous year. Since the start of the programme, the grant has been used to provide training to 8,505 parents in 147 local areas (this includes training directly commissioned by local forums, training offered through partnership working and training directly offered via TDC.)

Parents delivering training

96 of the forums reported that parents were involved in delivering training; an increase from 33 in 2009 and the total number of parents involved was reported as 466, increasing from 108.

	March 2009	March 2011
Areas where parents are delivering training	33	96
Number of parents involved	108	466

Parent carer forums often developed training for professionals to raise awareness of their experience of services as well as input their expert knowledge about the needs of disabled children and young people. A wide range of professionals received training, including many in universal settings.

Bromley

Parents are regularly delivering training within school settings, family and children's centres. A group of parents is being established to support inclusion in universal services.

Staffordshire

Parents are involved in the delivery of training around autism awareness. Parents have also delivered training in schools and spoken at events and conferences to raise awareness. A parent board member is undergoing training that will enable them to deliver training to other parents.

Links with services across the sectors

Parent forums have worked hard to establish working relationships with professionals across the social care, health and education sectors. 91% of parent carer forums demonstrated they were working actively across more than one service (in health, education or social care sector), with 70% working across all three.

Brighton

„*We have been involved in monitoring the quality and standard of therapy services in the local authority alongside heads from physiotherapy, speech and language therapy and occupational therapy services. We have also been involved in monitoring the supply and delivery of equipment as part of the commissioning strategy*.‟

York

Social Care: „Parents continue to be part of the short breaks implementation group, which is supervising the initiatives of the AHDC funding in York. Two parents are particularly involved in recruitment, assisting with eligibility criteria, applications for grants etc.‟

Bromley

"Education – „Parent Voice asked to form a small focus group to work with the local authority on proposals to review and amend the SEN Transport Policy. Across all three services – the Chair of Bromley Parent Voice sits on the Disability Strategy group, which is multi-agency.‟

Herefordshire

Health: „Forums have participated in the end of life strategy and been involved in widening the parent-befriending scheme to chronically sick children.‟

Social care: „Involved in Common Assessment Framework consultation work, children centre work and the commissioning strategy for the whole of children's services; Forums have also been involved in the process of reviewing all children‟s disability services.‟

Development of regional networks of parent carer forums

Headline

- Networks in all regions have been developed, providing opportunities to share experiences and disseminate learning, as well as acting as part of the communications structure from local to national, further strengthening the role of parent carer participation

Regional networks now operate in all nine regions, having developed over the last year. These provided the opportunity to network, share experiences, and remain updated about national and regional developments.

The regional networks provided significant peer support, as well as enabling the flow of communications from the National Network of Parent Carer Forums Task Group (NNPCF) to the regions and on to local groups. Forums are able to share good practice examples, challenges in working within their local areas, and participate in solution-focused thinking and planning.

Each region is unique and has their own regional network. Initially, the Parent Participation Advisors supported the development and facilitation of these and the cost of hosting the meetings and providing the equipment was met through TDC.

As well as enabling information sharing, such networking also creates opportunities for local areas to consider working together.

Havering, Barking & Dagenham, Waltham Forest and Redbridge held a joint commissioning process to appoint a domiciliary care provider for befriending and home and other carer services to disabled children, young people and their families in April 2011. By working together, parent carer forums were able to field two parent carers to take part in the commissioning process. The personal contact the parent forums have made through the regular regional cluster meetings has helped them to build more regular opportunities for contact and to facilitate cross borough parent forum discussions on health and other issues. This is becoming more important as local authorities in London look to work more closely together on other issues like commissioning.

The National Network of Parent Carer Forums

Headline

- A formal structure to enable engagement of parent carers in policy shaping and planning has been developed in the form of the National Network of Parent Carer Forums (NNPCF) and is developing credibility as a collective, influencing voice for parents

- A structure to enable effective communications between local forums, regional networks and the NNPCF task group has been successfully established

> *"Our strength is our shared experience."*
>
> **Strap line of National Network of Parent Carer Forums**

Introduction

The National Network of Parent Carer Forums (NNPCF) was established in March 2010 as a mechanism to support local and regional parent carer forums. The aim was to establish a structure through which the voice of parent carer forums could be heard, and parents could be involved in national developments and consultations; using the regional networks to facilitate this with two-way methods of communication between the local, regional and national networks.

The NNPCF comprises all the parent carer forums or participation networks that are now in existence across the country.

The NNPCF has a task group of nine regional representatives, (currently non-elected task group members) and the previous Ministerial Implementation Group parent representative, who was originally invited to take the lead to develop the network.

Aim of the network task group

The NNPCF‟s main aim is to promote the participation of parents in all elements of policy work that relates to services and provision for disabled children and their families and has produced the strapline „Our strength is our shared experience‟.

The aims of the group include acting as a conduit for ensuring regional and local forums consult with and participate in regional and national developments.

The National Network of Parent Carer Forums Task Group strives to ensure that good practice, knowledge and shared expertise continue to grow to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer groups across England, individually and as a collective voice.

Ways of working

The NNPCF task group has developed governance structures and membership criteria and is on task for meeting agreed objectives. All regions are represented and as the forums develop, the nine regional members will be elected democratically and stand for a defined period.

All local parent carer forums are eligible to become members of NNPCF as long as they can satisfy minimum entry requirements. Further clarification about membership is included in the membership policy.

Key achievements

The NNPCF task group has made significant progress over the last year and has developed into a strong and effective network that has achieved, and exceeded its aims and actions.

- Increased the response to a number of consultation exercises, ensuring that parents‟ voices are heard and shaping policy making

- Developed a „what works for us‟ pro forma to capture good practice and successes within local forums, distributed and supported through the regional networks
- Raised the profile of parent participation through a number of media, such as TV and radio interviews, as well as presenting at national and regional conferences
- To ensure a „one-voice‟ message, the network met with MPs to influence policy development
- Met and begun developing relationships with key government departments and a number of national organisations (for example, the Care Quality Commission)
- Produced reports outlining key issues in relation to parent carer involvement
- Provided a conduit for formal communications between national, regional and local forums and networks
- Progressing towards becoming an elected independent national network of parent carer forums
- Developed own website
- Secured additional funding from the Department of Health to support sustainability of the network
- Developed and distributed a range of products to support forums

> *"A great communication with some really powerful messages."*
>
> **Parent commenting on one of the NNPCF Communications**

Parent carer forum chair, East Midlands

"The National Network is essential to the ongoing development of parent participation – we need to make sure that we have support at a local, regional and national level and that our voice is being heard nationally."

PODS (Parents Opening Doors) Telford, West Midlands

"I would like to stress that without the support of the regional representative from the NNPCF we wouldn't have felt able to write a campaign letter to our local leaders. This letter has resulted in a meeting planned for the end of March to discuss the future of disabled children"s services with council leaders and service managers. This has shown that our forum is being taken seriously and our opinions sought."

Going forward

The task group believe that the network should strive in the long-term to become an independent organisation, with its own constitution and budget. Local forums should also be aspiring to a model that reflects the values of parents speaking for themselves, rather than others speaking on their behalf, and would want to ensure that the NNPCF demonstrates and models the same independence, parent leadership and structure that are vital to strong, effective participative working.

In the short term, the NNPCF will continue to be supported by the DfE, who will continue to fund a support partner for parent participation work. In the long term, the NNPCF will be striving to seek funding to enable it to become a fully independent organisation that will use the support of a wide range of partners including those organisations with which it is already linked such as Contact A Family and the Council for Disabled Children.

All members of the current task group remain committed to the development of the Network and highly value the positive influence it believes it can bring to bear on services for disabled children and their families with the continued investment in and support for parent participation on a local, regional and national level.

Community leadership programme

Headline

- Three community leadership courses have been delivered, enabling 55 parents to receive training that has equipped them with the skills and confidence to be able to run parent carer forums
- The purpose of the training was to improve the long term sustainability of parent carer forums by equipping parents with the skills and confidence to maintain the forums

Throughout the period of support TDC advisers identified recurring challenges. These included issues around sustainability, governance, managing group dynamics and challenging situations. Some training was available to local forums but often this was not specifically tailored and did not meet all the needs of running a parent carer forum.

TDC advisers working with an associate trainer developed the course aims and content:

- To engender stronger, more inclusive participation groups
- To develop further understanding of policies, procedures and legislation
- To develop a better understanding of local authorities and how best to negotiate
- To develop an understanding of how to lead and maintain groups

Learning outcomes and benefits - impact of the course on forums

Every session was evaluated and changes made about format and method of delivery. Generally the course was well received and all participants said they enjoyed it and that it had made a difference to their forum. Participants said that they were clearer about setting aims and objectives and how they fit into the bigger picture of their area. Several said it had made them think about their own style of leadership and how they could improve on that to ensure everyone in the group is valued and able to participate fully. They had a better understanding of the roles people take in groups, the processes groups go through and how to resolve conflict positively.

> *"I feel better now about dealing with some of the issues that come up in the group. I will be able to sort things out. I will be more aware of undercurrents, positive and negative, how people are affecting each other and how I am impacting upon this."*

The majority wanted to revisit their governance arrangements to determine their vision and the role they can play locally. They said that they had a better understanding of how local authorities work and some of the pressures they are under as well as assessment processes and entitlement. Participants enjoyed learning new things and particularly valued the input on legislation, safeguarding and group work skills.

> *"We are stronger and more focused and have the skills and knowledge to speak out. I„m more confident about the various strategy groups and panels I sit on."*

> *"I feel better equipped to attend meetings with professionals and more able to challenge decisions whilst remaining respectful."*

Group members enjoyed working with other groups, sharing information and ideas. They reported that they now felt better equipped to network with other forums.

> *"We have gained lots of knowledge and understanding and its given lots of ideas. This has strengthened me and I feel more a team player than before."*

Impact on participants personally or professionally

Parents of disabled children come from different socio- economic and professional backgrounds and have a range of life experiences. It was important to consider this when planning the course in terms of pitch, pace and content in order to meet the needs of all the group participants.

One member of the group has written a guide for local parents on their rights within the education system, whilst another member who had difficulty in written note-taking illustrated the sessions. This participant has now gone on to college where her method of note-taking has been accepted and other students are finding them useful. The majority of feedback reported that group members felt more confident and better informed.

"My confidence and self-esteem has been boosted, I"ve proved to myself that I can do this."

"I feel more knowledgeable about certain things and know where to go if I have problems. I feel more empowered. I feel more confident as a result of the course as I now have knowledge of policy and procedures."

"Three members of our committee, myself included, attended the community leadership course and this has further developed our individual skills in running a committee and has helped us to understand the sometimes conflicting world of governance and policies and procedures relating to government departments and how best to manage and lead a parent forum into the future. From this we have built up a brilliant link with a parent carer forum and we are in the process of attending each other"s meetings to share best practice."

"It‟s a generic course, not tailor made to me but each week I found a nugget of gold that inspired. This training needs to be continued."

Whilst the course was positively received and the learning reported to benefit forum development as well as participants individually, the three courses held were only a start to support the development and sustainability of parent forums. This pilot was to test the validity of a training course and now needs to be developed further in order to reach more parent carers. Moving forward, it is important that parent carers are more actively involved in developing leadership courses and in taking charge of the delivery.

Increasing the involvement of black and minority ethnic parent carers in parent participation

Headline

- Three pilot projects have been successful in increasing participation of parent carers from black and minority ethnic (BME) groups and have produced products that will be useful in supporting other forums to be effective

Parent carer forums have had mixed success in engaging with black and minority ethnic (BME) parent carers. The additional barriers and challenges faced by parent carers in many BME communities have made it more difficult for some to effectively engage with the established local forums and ensure that their views, wishes, and opinions are represented within the strategic planning and decision- making processes with which local forums are engaging.

Purpose of the pilots

The purpose of the pilots[7] was to actively engage more BME parent carers in parent participation in three localities. The aim was to identify which methods were successful and to identify learning to be shared with other areas.

The pilots

The three pilot areas were able to access up to a maximum of £5,000 to support the project and to enable the organisation to offer a more proactive and intense delivery for the project. In view of the additional resource, each pilot was required to develop a product of some type that could be used to develop learning and that would be shared across all local parent carer forums.

In **Leicester City**, the local area had supported an organisation named Aqoon to produce a DVD for Somali parents and carers, which provided information and advice on enabling disabled children to access a variety of services. The forum was keen to develop links with Somali parents.

In **Hull**, a parent from one of the local forums wanted to develop a regional network for BME parents and carers to support and develop the involvement and participation of BME parent carers on a regional and, subsequently, local level.

In **Tower Hamlets**, the local parent carer forum had expressed an interest in developing their ESOL (English for speakers of other languages) course to include particular elements that encompassed some of the issues and elements around participation.

Each of the three projects successfully increased the participation of BME parent carers. Each project experienced different challenges and successes and each have particular issues in relation to the sustainability of the work.

The products

Midlands – podcast outlining the process and key learning points and challenges by the facilitator and members of the Somali Parent Carer Group.

North – DVD created by disabled children and young people during the regional event and podcast by the pilot project lead.

South – Lesson plans for the ESOL participation classes were developed.

These will be distributed on a DVD to all parent carer forums, along with a full report[8] to inform them of the work undertaken and a summary of the learning points gained from the three pilots.

Wider benefits

All three projects were effective in promoting the participation of BME parent carers with the aims and agreed outcomes met.

The three pilot projects all took very different approaches to increasing the participation of BME parent carers in the local and regional areas. Whilst there is much national debate about the impact on social cohesion and community of having BME-specific groups, what is clearly evidenced is that for the projects who took this approach, the barriers that parent carers faced in participating within the main local and regional parent carer forums did require an alternative approach. These approaches were successful in engaging parent carers who had not previously participated in their local forum or regional networks.

Much use was made of existing contacts and links with organisations that were already involved with parent carers from black and minority ethnic groups, and this is a key to developing work; to utilise existing links and resources. Local authorities and health partners can contribute in ensuring they share the links and networks that may have already been made, or services that they may be resourcing and commissioning for other work to enable parent carer forums to link into these and provide the best possible reach. Again this emphasises the needs for local authorities and health partners to work closely with their local parent carer forums to ensure this is able to happen.

There remains the need for learning for some parent carer forums in terms of inclusion and ensuring that their forums are welcoming and open to parent carers from a diverse range of backgrounds. Many forums have themselves identified this is an area where they would welcome some additional support. Some forums have already forged strong links with some of the minority communities in their local area, and the tools, skills and methods of achieving this also needs to be shared.

Whilst there are many demands on parent carer forums, this small piece of work demonstrated the inherent benefits for the parent carers from BME communities who were involved not only of engaging in participation, but in terms of peer support and being better informed about local service provision and the local authority, are likely to have long-term benefits for the parent carers involved

Positive outcomes of parent participation

Headlines

- Evidence is emerging about the positive outcomes linked to effective parent participation, both for parent carers, disabled children and young people, for the statutory services that seek to provide appropriate services and for the wider community

- Effective parent carer participation has had a positive influence on commissioning practices, leading to increased value for money in service provision

- Involvement in participation has increased the confidence of parents, improving self-esteem, leading to a range of improved outcomes for parents

Participation influencing commissioning and service delivery and planning

Commissioning officer, Peterborough City Council
"Parent participation has influenced the choice and quality of the short breaks services we buy by making sure we ask the right questions in applications and interviews and influencing processes such as the entitlement framework, so I consider the local authority to have better value services as a result of an ongoing process of parent participation."

For local areas, the idea of meaningful parent carer participation and becoming partners in policy and decision-making has not been without difficulty. However, all local areas have made progress in ensuring parents are consulted and involved and in many instances not only for the developments around specialist disability services but across children‟s services as a whole.

Parent carer participation has added value by helping to design services that are more appropriate and result in better outcomes for children and their families. Some local areas have provided evidence that decisions about service provision and delivery have been directly affected and influenced by parent carer participation. Parent carer participation has unquestionably led to improved outcomes for disabled children, young people and their parents and carers, as well as for local authorities and primary care trusts. However, empirical evidence to support this is difficult to determine so early into such a radical programme of transformation when services are still evolving. Qualitative data shows that parent carer participation has led to improved service provision, changes in traditional decision- making, elimination of duplication and, ultimately, saved money.

Parents from **Trafford** Parents‟ Forum were part of the commissioning process for short breaks. A synopsis for each bid was written in a user-friendly format and parent evaluation and scoring documentation was developed giving parents‟ information around who the project was for (age, group, disability etc), how many children could access the project and how the projects would plan for sustainability after funding.

Following interview, parents‟ suggestions were taken to the provider and changes were made and brought back to parents. This resulted in happy parents feeling they had a real influence on their service and provided Trafford with a successful service being accessed by lots of children.

This provided fit for purpose services, rather than services that would have been commissioned and not used, thereby wasting money.

Shropshire Parent and Carer Council (PACC) was involved in deciding that the area should support the implementation of the Playbuilder initiative in Shropshire.

The outcome of sharing this information with the Playbuilder team was a fundamental change in how the scheme was implemented for the three sites identified for funding from the short breaks project.

The result of this parent participation is that the short breaks funding committed to the Playbuilder initiative will secure real and meaningful gains for the community of families with children with disabilities or additional needs in Shropshire. For Shropshire Council it will deliver value for money that otherwise would not have been achieved.

Volunteering

The financial contribution to support the development of parent carer forums has been small at local level, and whilst some local authorities have funded participation workers, many have not. The involvement of all of the parents and carers in the forum is voluntary. Many parents volunteer for up to 14 hours a week, whilst a few active parents can spend up to 35 or more hours per week attending meetings, supporting other parents or undertaking administrative duties for the forum. Being an active member of a parent carer forum enables parents to be a part of the „Big Society‟ in a way that is conducive to their caring responsibilities.

Forums report that parents volunteering their time can have raised self-esteem and develop other skills and experience.

Families Acting for Change **Essex** (FACE) is led by a chair who works virtually full-time on a voluntary basis to canvass parent feedback, attend service strategy meetings with the local authority and all five PCTs to feed parents‟ views into service delivery decisions. She arranges training and development for other parents to enable them to feel empowered to do the same.

Through this volunteering role, the chair is developing business and meeting skills, line management and negotiation skills. She is also hoping that she and some of the other parents will be able to become trainers themselves so that they can generate an income for themselves through delivering learning to other parents and professionals.

Engaging what has traditionally been a hard to reach group of parents who by their very nature often have complex and demanding caring responsibilities, has been challenging. However, as parents have seen that their commitment and volunteering has achieved results, they have been willing to continue to volunteer their valuable time. There has been a cost to enable this level of volunteering, which has included the need for local areas and forums to support basic transport costs, childcare costs, (it is typically significantly more expensive to provide childcare for disabled children than non-disabled children), interpreting and venue costs. Forums have also had to negotiate some of the complexities of caring for disabled children with their volunteering and arrange events and meetings to support this. These costs are variable depending on the geographical nature of the local area, the diversity of the local community and the particular needs of those parents involved.

Developing opportunities for parents to return to work

Many parent carer forums have enabled parents to consider the opportunity to return to work. Volunteering can often help to build confidence, develop skills, and provide experience for parents who previously may have been denied these opportunities. For some parents, this has led to them considering how they could potentially commit to working. This has resulted in some parents being successful in applying for paid employment. Many forums report the very positive outcomes of parents‟ involvement, and the development of forums in this area, as evidenced below.

Telford and Wrekin

Parents Forum PODS (Parents Opening Doors) has been commissioned by the local authority to manage a short breaks provision entitled POLO – Parents Offering Leisure Opportunities. The forum was able to recruit a parent carer as a paid co-ordinator of the service. This also promoted close working with the joint commissioning manager from the local area who offered training and support to develop the role and provision.

Bedfordshire Families United Network (FUN), a local charity run by parents of disabled children with the Day Care Trust, has developed a model to train and develop parents of disabled children to become paid disability awareness trainers. As well as delivering training to service providers and professionals, parents work towards achieving the „Preparing to Teach in the Lifelong Learning Sector" award, which will give them a recognised qualification in adult learning.

Calderdale

Two parents will be trained to become trainers employed by the local authority. These parent trainers will be paid to deliver a course created by the parent forum to family workers across Calderdale, and each time the course is delivered the Parent Carer Council receives income.

Calderdale employs three parent staff members, pays parents to be advisers to the local authority and creates opportunities for volunteering to develop skills leading to paid work. One parent is being paid by the local authority to work with the Family Information Service to produce an information booklet for families.

As parents of disabled children are three times less likely to be in paid employment, and families caring for disabled children are more likely to live in poverty, this is a particularly positive outcome.

Parent forums leading to other support for parent carers

Whilst parent carer forums have had responsibilities for ensuring that they have used their parent participation grant to deliver their work, many forums have successfully sought additional funding not only to support participation, but also to source other support for families of disabled children and young people.

Redbridge

"We successfully bid with Haven House for Department of Health funding for the Expert Parents programme. Based on the Expert Patient model, it was centred on understanding the needs of parent carers as the front line carers of our children and young people.

"We provided training to nearly 300 parent carers, most from BME families, over three months from January to March 2011. We are finalising the evaluation now but overall, we had a great response from parent carers who all want the programme to continue. The local authority has committed to fund the project going forward and we are going to apply for equal funding from Health in early June."

Emotional wellbeing of parent carers

Caring can have a major impact on carers" health and wellbeing, with carers significantly more likely to be in poor health - both physical and emotional - than people without caring responsibilities [9]. Parent carer forums report that a positive outcome of being part of a forum is the added emotional support and sharing opportunities that are provided, which enhances the emotional wellbeing of carers. As this enables parent carers to continue to effectively care for their children, this is a considerable benefit of being a member of a parent carer forum.

Factors of success and ongoing challenges with parent carer participation

Headlines

- Empowerment of parents is bringing about an organisational cultural change in the way that services are planned and commissioned

- Parent carer participation fits with the vision of the „Big Society‟ as it supports local involvement

- Ensuring there are continued development opportunities for parent carers, that new parents continue to be recruited, together with succession planning, is key for forums

- Local parent carer forums and the national and regional structures are likely to continue to require support for some time, so that progress can be sustained and structures can become embedded

Outstanding progress has been made in strengthening and developing participation over the last three years. The data confirms and supports the significant developments that have been made and the cultural change that has come about through the evolution of parent carer participation. From our analysis of the evidence, some of the key characteristics of strong parent carer forums include:

- A strong base of parent carers involved
- Parent carers are clear about the aims of the forum
- Forums are pan-disability and are not issue specific
- There are support and back-up systems for those in leadership positions
- Parents have to be willing to engage and work in new ways
- Forums need to be able to develop and devise governance structures which help them manage challenging and difficult situations

- Forums do not rely heavily on one or two individuals, but a range of individuals
- Forums have been able to identify learning needs and gaps, and been able to seek appropriate support
- The strengthening and development of parent carer participation and parent carer forums is one of the strongest legacies of the work undertaken in the last three years

Links to the 'Big Society'

Meaningful engagement of parents in local and national service delivery is fundamental to the vision of the „Big Society‟.

> *"Building the Big Society is not just a question of the state handing over the reins of power and hoping that people will grab them. We‟ve got to actively help and encourage people to play their part. The rule of this government should be this: If it unleashes community engagement – we should do it. "*
>
> David Cameron

The development of local parent carer forums has had a significant impact on working in partnership with local government and health commissioners to make decisions about service provision, eligibility, commissioning and evaluation. The development of the NNPCF enables the local and regional forums to have a voice and inform central government of issues that are being faced by local and regional forums to help inform policy.

The development of parent carer forums and parent carer participation supports the three main tenets of the Big Society:

- Social action.
- Public service reform.
- Community empowerment

Challenges and barriers for parent carer forums

Despite the significant developments in parent participation, it is important to note the many obstacles that parent carer forums face, and are likely to continue to face.

By the very nature of being parent carers, it can often be difficult to engage parent carers and widen the membership of forums and groups. This can sometimes result in a disproportionate level of responsibility lying with one or two members of the forum. This in turn can be a challenge if they become ill or need to take time to care for their children. Capacity remains a significant challenge and a barrier to forums being able to participate as fully as they may wish to.

This can also be a challenge for forums that have been particularly successful, who cope with many competing demands and the expectations placed on them. Setting clear boundaries about involvement can assist with this.

Some forums have experienced challenges as they have become independent. In many areas forums were initially supported by grant recipients who were voluntary sector, parent partnership and, sometimes, local authorities. As forums have developed and become independent in some areas this has caused some conflict with previously supportive partners. It is an inevitable part of the journey, but challenging nonetheless.

Lack of a common understanding of participation has also led to challenges Professionals can have very different understanding about what is meant by parent participation. The nuances of the differences in approach have caused tensions. Continued work to ensure there is a shared common understanding about participation is necessary. These difficulties have been further evidenced in areas where there are dichotomous views between the parent carer forum and the local area about how participation should be developed.

Engaging with parent carers from hard to reach communities continues to pose challenges for some areas and needs continued development and support. Some forums have excellent examples of good practice in this area and the continuation of regional and national networks will enable this work to be disseminated.

For some areas, very practical issues contribute to their challenges. Large geographical areas and a lack of transport infrastructure pose difficulties to some forums in reaching out to their whole population and encouraging a wide range of parent carers to engage.

In other areas, it has been particularly difficult for forums where there has not been strategic commitment from professionals who most need to engage. This has led to delays and blocks and in turn has dampened parental enthusiasm. Ensuring that support is available to independently challenge in these areas has been and remains vital.

There have sometimes been challenges reported when the key individual officers have either left or moved post. Building new relationships can be time-consuming, which is another capacity issue for parent carer forums.

Other barriers have been experienced when there have been elements of tokenism in relation to participation. In some local areas, a few handpicked parent carers were individually invited to be part of strategic planning, rather than ensuring there was the true representation that would be achieved through working with the local forum.

In areas where there have been very particular challenges, parents had been disillusioned by numerous previous consultations and involvement exercises that had led to no change, or where attempts at participation had not been successful. It was, in some areas, more difficult to re-engage parents who had already invested energy and commitment but who had perceived their efforts had been ignored, or misused.

As in any group setting, some groups have experienced „power struggles‟ where particularly dominant members of the groups have tried to pursue their own agendas. The need for a wide range of members and strong governance policies are key to managing these difficulties and to making the forums work for everyone.

It will be essential that parent forums are supported to engage with local authorities while they seek to make efficiency savings. Early indications suggest that local authorities often find it more difficult to engage with parent forums when they are themselves going through significant change programmes. Parent participation can support the drive towards efficiency.

As parent carer forums face these challenges, the need for local authorities and health partners to support them is only increased. Whether or not there is some continued national support such as the grant to local forums,it is support from within the local area that will be essential. As structures and key contacts in local areas change due to reconfigurations and reorganisations, it is vital that parent carer forums remain fully involved and updated about these. Practical support, both in terms of grants and support in kind is also particularly helpful and demonstrates a local authority or health partners commitment to the parent participation agenda.

What is clear is that parents working as partners and participating in all areas of decision making leads to better outcomes for disabled children and young people, and the significant transformation that has been evidenced in this area needs to be sustained and developed.

Section 2: Transforming short breaks provision

Increasing access to short breaks services

Headlines

- Over 105,000 more disabled children are receiving short breaks – an increase of 184% since 2008
- Reach – the proportion of disabled children receiving short breaks as a percentage of the total child population – has increased to 1.36%
- Better value for money is achieved when access to short breaks services is made easier
- Whole family activities have proved to be excellent value for money – they are enabling main carers to share the responsibility of caring and be supported by other parents

Numbers of children receiving short breaks

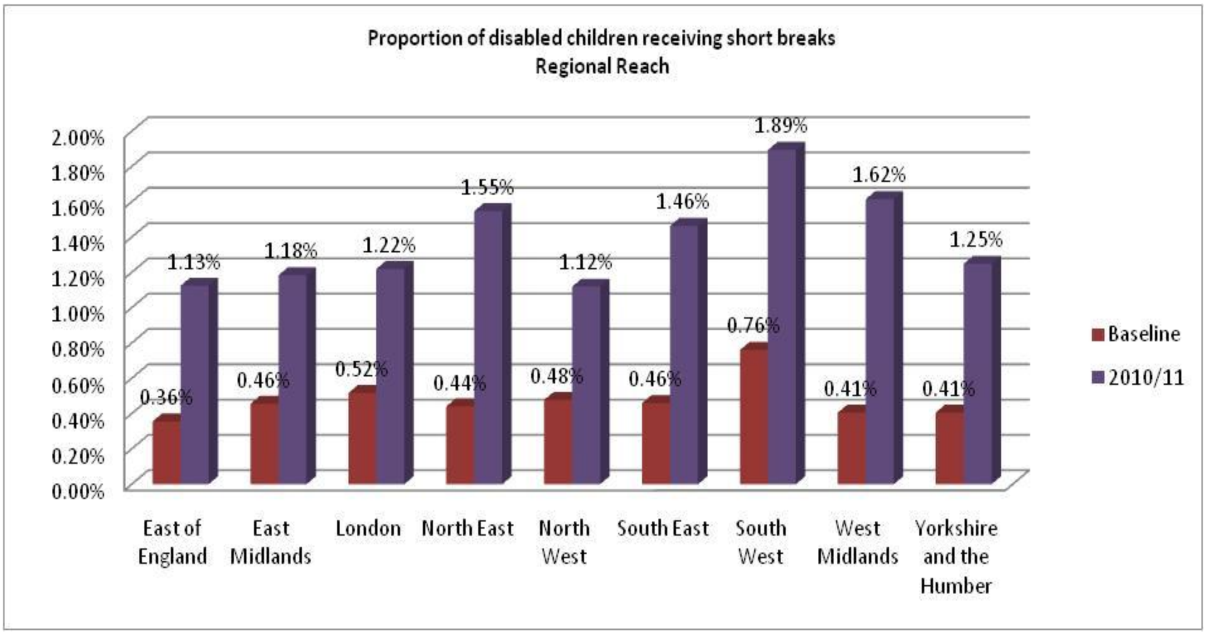
Number of disabled children receiving short breaks services	Baseline	10/11	Increase	% Increase
Number of children	57,383	162,831	105,448	184%

The number of disabled children receiving short breaks has more than doubled over the course of the programme. Almost 163,000 children per year are now having regular breaks, which is an increase of over 105,000 (184%). This is a far greater increase than was projected at this point last year, when the estimate was 91,000. Not all areas have increased their numbers at the same rate. The average percentage increase was 208% and the greatest was over 1,400%. The majority have increased by between 100% and 400%, with 12 areas increasing numbers by more than 420%, and there have been no areas that have not increased numbers. Of course, not all areas started from the same baseline. There were several areas that had had a longstanding policy of offering smaller levels of service to higher numbers and others that had taken a very focused approach and offered services only to those assessed with the highest levels of need. Neither approach was wrong: they were both ways of managing a finite resource. The investment has enabled authorities to revisit their access policies and look at how more services can be provided to more children using a tiered approach.

Reach

As there was such a varied baseline at the outset of the programme and given that there was little reliable data on disabled children to work with, there was uncertainty about how to calculate the numbers of children who might need short breaks. This number is reliant on multiple variables, some of which are interrelated, with factors such as family resilience, local community support and general access to universal services. To enable local areas to make a start with projections, the ballpark figure of 1.2% (the number of children receiving short breaks as a proportion of the total child population) was used as a starting point. This figure represented the proportion of children likely to be in receipt of higher rate disability living allowance and thus the most severely disabled child population. This figure was scientific, but it allowed areas to begin making plans. It also enabled some more direct comparisons to be made across areas about numbers of children having short breaks.

In this way, the number of children receiving short breaks as a percentage proportion of the total child population was measured in every area and was termed the "reach" of the local area. At the start of the programme, the national reach was 0.48% and has increased year on year to 1.36%, an increase of 0.88%. Again, there is variability across areas with a range of 0.42% to 5%, the average being 1.4%. Sixteen areas[10] have a reach of over 2% and 24 others are above average. The majority (88) are in a cluster between 0.9% and 1.4%. Only three areas in the country have a reach of less than 0.5% and all areas have increased their reach. There is also regional variation, with the South West, South East, West Midlands and North East regions having considerably higher reaches than other regions. The lowest regional reach is the North West.



Impact of reach on cost per child and value for money

Clearly, the number of children receiving short breaks greatly affects the cost per child of short breaks. Indeed, most of the areas with a reach well above average have the lowest cost per child in the country. The average is £4,938 per year and the lowest in the country is £604 (calculation includes management and supporting infrastructure costs). Factors that impinge on costs will include the proportion of residential overnights, the amount of breaks available in universal settings and the proportion of children with severe and complex needs.

There is also the issue of the number of units per child to be considered. A low overall cost per child may look appealing, but if the majority of children are only receiving low numbers of units and are not generally satisfied with the amount, the overall value is lessened. TDC therefore used a framework that took a number of variables into account to calculate an overall value for money score. Factors included:

- reach
- cost per child
- average nights
- hours per child using each service model
- unit cost of each service
- number of children receiving direct payments and the amount per family allocated for these

On this basis 15 areas emerged as having data that supported a „well above average‟ value for money score, with a further 23 being above average. A small number of areas had high reaches but their overall value for money score was less than average.

Further analysis of these 38 high-achieving areas showed that they were generally areas that had strong relationships with parents; there was also evidence of good partnership working with other stakeholders. Most had endeavoured to put open-

access frameworks or local offers into place, with a range of services available to all families, and were demonstrating some examples of innovative practice.
This analysis tells us that reach is a very important factor in achieving value for money in short breaks. It is also clear that significantly higher reaches are attained when access frameworks and local offer models are put into place that have some level of service accessible to all disabled children without the necessity for formal assessment. However, reach is certainly not the only factor that has to be considered.

Value for money is attained by a combination of cost-effectiveness and user satisfaction, and the level and quality of service received by users contributes to their satisfaction. Partnership with parents in planning and commissioning leads to the likelihood of services being delivered that are fit for purpose and are what children and families really want, further increasing the satisfaction rates. Working closely with providers, investing in training of workers and using feedback to continually improve services leads to the greater likelihood that better quality services will be provided. Having a range of service models is also crucial. If there are a high proportion of breaks in high cost residential models and less general investment in group-based services, inevitably the overall cost per child will be considerably higher. Conversely, investing too much in group-based services at the expense of limiting the amount of individually supported specialist services could potentially lead to children with severe and complex needs being disadvantaged. Clearly, an effective balance of services must be struck.

The TDC value for money framework provided a useful mechanism for local areas in determining an effective balance between reach, the range of models offered, unit cost and sufficiency of units per child. This has given areas a good starting point in their work to achieve better value for money.

Numbers of children receiving short breaks across the range of service models

Service Model	Number of children at baseline	2010/2011	Increase
Overnights	15,090	25,878	71%
Family-based or individual day care	20,788	48,370	133%
Group-based short breaks provided during the day: specialists	25,589	88,419	246%
Group-based short breaks provided during the day: non-specialists	8,419	44,858	433%

Increases in the number of children receiving short breaks across the range of service models can be seen, with the greatest increases in group-based services. The number of children in the above table totals more than 207,000, indicating that many children are receiving a mixed model of service provision.

Appendix III provides an explanation of short breaks service models

Improving access to services

All areas are clear that access to short breaks has been improved and certainly the data collected supports this. There are now no reported waiting lists for services and the progress reviews of last year indicated an explicit commitment from all areas to establish single points of access.

Local offers

Where local authorities have moved to an entitlement model and away from a formal assessment for every service, more children and young people are accessing universal services, leaving social care intervention to be used only when it is necessary. A growing number of areas are developing „local offer" models of entitlement, which centre on a tiered access framework developed by the local authority that sets an easy to measure criterion for accessing a minimum number of hours. For example, Enfield offers a minimum of 100 hours of any level of group-based activity to all children who attend special schools or are in receipt of higher rate disability living allowance. No assessment is necessary to determine entitlement, as the child has already been assessed as needing special education or additional disability benefits. This does not preclude any family requesting a formal assessment but it takes many children out of the bureaucracy of the assessment system.

Parents have welcomed being involved in the development of their local area"s eligibility criteria.

Enfield

"There is no longer the necessity for a social work assessment. Of the 700 children and young people receiving short breaks, only 150 have had a social work assessment. Parents now know how to self refer and they understand the resource allocation process There is no longer any waiting list for short breaks. Schools are encouraged to refer families for additional support where this would be helpful."

Peterborough

"Our local entitlement framework has significantly increased access to short breaks that do not require a social care assessment."

Where local areas have not developed an entitlement model they have tried to be clear about the thresholds to ensure fairness and equity.

Bedford Borough

"We know through our mapping exercise that we are now offering access to a service to groups who were not catered for, particularly young people with challenging behaviours. We are further developing eligibility criteria and expect to have a local offer in place to ensure wider access to services."

Improving information to families and promoting short breaks was crucial to opening up access. Many local areas have improved information available to families via newsletters, websites and the Family Information Service. This has increased the take-up of short breaks, with outreach staff employed specifically to reach families and coordinate the short break services.

Essex

"Newsletters are posted with termly SEN parent partnership newsletters directly to all parents who have children supported through School Action Plus or children who have a statement of special educational needs (approx 9,200). They are also circulated to children"s centres, schools, libraries, child development centres, children with disabilities social work teams, special educational needs and children with additional needs services, umbrella forums for support groups for children with disabilities and short break providers."

Buckinghamshire

"We have used a significant amount of the AHDC funding to improve open access to short breaks for all disabled children. This means we have approximately 400 parents with disabled children who haven't needed to access social care to get a short break service.

We are also in the final design stages of a parents" directory outlining all services available to disabled children, including short breaks, and this will greatly improve the information that parents have about what services are available and how to access them. Parents have been involved in the production of the directory.

Our eligibility and access to short breaks criteria is in the process of being published online."

Many local authorities reported on their efforts to improve inclusion and thus increase access to universal services.

Greenwich

"We have worked well with sports and leisure services and now have a range of services and activities that can be accessed by disabled children. These include a range of swimming activities, trampolining, football and specialist wheelchair football and basketball. We have engaged the voluntary sector to support this."

Rotherham

"We have successfully commissioned provision in 2010/11 that has increased the volume of provision, its geographical spread and addresses access by BME groups. This consists of a BME befriending service and a BME-specific young people's activity group."

Hull

Hull has developed a system that ensures parents‟ access to services is improved. They have developed and opened up services, ensuring information about services is widely available across the City via the Family Information Service, community groups, workers and the parents‟ forum. They have ensured that parents understand the formal processes for certain services and that they have a good understanding of how to access services. They have ensured that workers also understand what services are available to the public so workers can promote them. Parents report an improvement in being able to access services and consider that they are age and developmentally appropriate.

Moving forward

There are a significant number of areas remaining where access frameworks do not offer any automatic entitlement to any disabled child and where access is only possible through a formal assessment. There are also areas where the reach is less than 1% and some where there have only been modest increases in group-based non-specialist services (generally the services that are easiest to make open-to-all).

There also still exists some resistance in several areas to provision of activities for „whole-families‟. Where these are provided, they are always well evaluated and parents state they value the opportunity to combine support for themselves with children‟s activities. However, in some areas they are viewed as not being breaks from caring as the main carer is still present. They do appear to give excellent value for money though, as when parent carers perceive that they are being actively supported and listened to, their satisfaction levels increase and they are less likely to need more costly models of service. All local areas should give consideration to offering this model in their range of provision.

One worrying issue is that many areas worked hard to partner with universal services to enable easier access to youth clubs, after-school activities and so on but some of these services are facing severe cuts to provision in the coming year as public service funding decreases. This is likely to have an adverse impact on their capacity to be able to go on providing services to disabled children and young people and is going to be a major challenge to short breaks commissioners in the future.

Growth in volume of short breaks services

Headlines

- Significant growth in the volume of short breaks provision has been demonstrated. An additional 193,000 nights (an increase of 33%) and over eight million additional daytime short break hours (an increase of 135%) are now being provided each year
- Increased engagement of parents in the commissioning process and a greater level of partnership working with providers has led to services being developed that are giving better value for money - more services are being delivered to more children at lower unit cost
- Spending on short breaks has increased nationally by £251 million, a growth of 71% since 2008

Growth in short breaks provision

There have been significant increases in the number of short breaks that have been commissioned by local areas. Growth has been seen in all of the different models.

Nationally, over 193,000 more nights are being provided each year – an increase of 33%. Short breaks provided during the daytime have increased by much greater levels and over eight million additional hours, per year are being provided to disabled children across the range of different service models, representing an overall increase of 135%.

In family-based short breaks, almost six-and-a-half-million hours are now provided, an increase of 87%. In group-based specialist services, over five million hours are being provided; an increase of 175%. The greatest increase, however, has been seen in group-based non-specialist short breaks. This was the service model where the least number of breaks was available (only 10% of hours provided by this model at baseline). The increase in hours has been 289%, with almost two-and-a-half-million hours now being provided, and this model of provision now represents 17% of the total number of hours. Specialist group provision has also increased in proportion from 31% to 37% of the total number of hours provided.

Services based on need

Local areas have become more aware of the needs of their disabled children‟s population through rigorous strategic needs assessments. At the outset, few areas had good data about disabled children, yet they now value the results of their hard work in data collection and analysis and have used the LAIMP (the interactive tool set up by TDC to collect data from local authorities) to inform their planning. More importantly, it is becoming the norm to work with families in planning and commissioning. Parents are involved in choosing providers and in reviewing service specifications. Needs assessment was previously seen as a one-off event but this view has shifted to one of being integral to the continuous commissioning cycle. Demonstrating responsiveness to the voice of families has led to better take-up as the services are what families really want. Feedback is used to inform evaluations and improve the quality of services.

Waltham Forest

The introduction of a framework agreement has given the local area much more flexibility to commission services based on evaluation and feedback from parents/children. The relationship with providers continues to develop and the PCT is commissioning sector-wide including hospices, continuing care and domiciliary services.

The pattern of growth reflects what local areas have been saying parents and children wanted - a greater range of breaks in ordinary settings and increases in specialist support.

Redbridge

“There is now a wide range of activities on offer and we have moved away from „sitting‟ services to services based on activities that children and young people enjoy. There are many more opportunities for outdoor and adventure activities.”

Increase in number of providers

Most areas (88%) report that they are commissioning from a greater number of providers. In particular, there has been an increase in the number of voluntary and community sector organisations, particularly small, local groups, who are being commissioned to provide services.

Newcastle

“There has been a significant increase in the volume and range of services with a wider range of providers. We have drawn on the culture and arts that are available across the city to provide innovative and creative new services, many of which are from the community and voluntary sector.”

Effective partnership working was reported to be a key feature in developing the market: in other words, parents and providers are being involved in developing new and existing services. Provider forums have been established in most areas and have been used to stimulate the market and improve the quality of services. Facilitating discussions between providers and parents has been key to ensuring better understanding of what type of services will be most helpful. 84% of local areas reported that they believed that they now had better partnership working with providers.

Croydon has commissioned from a broad range of third sector providers, some of which are new. While some are small local providers, others are national organisations.

Nottinghamshire

An approved provider task group is working with providers to continue to develop services, linked with opportunities for quick developments, to meet gaps across the county.

Parents as partners in commissioning

Commissioning practice in local areas has become more proactive and responsive to the assessed needs of the disabled children‟s community. The increasing involvement of parents in planning and development of services has been instrumental in this transformed approach.

Portsmouth

"The commissioning of all short breaks services has been based upon the needs of parent/carers and children and young people with disabilities. There is a wide range of provision available for families to access via self-referral, which has enabled us to offer a fair and transparent approach to accessing short breaks services. We have been able to offer a wide range of short breaks services that are age appropriate and that children and young people with disabilities enjoy attending. Services are starting to become more joined up and parental engagement has improved significantly."

Parents themselves report being better involved in the design of services and use of resources, as well as in the short-listing and interviewing process for programme staff and providers.

Parent representative on Sutton Partnership Board

"Something quite magical happens when people sit down together, talk, listen and work things out. Barriers come down, fear and ignorance fly out the window and respect, understanding and goodwill takes their place. With parents actively involved in shaping services based on what we know our children and families need, every penny of funding is put to better use. With the economic difficulties now facing us all, this wise and effective use of financial resources is crucial."

Growth in short breaks spending

Over £270 million of revenue was allocated by DfE to local authorities in the 2007-2008 comprehensive spending review period, ring-fenced for the purpose of transformation of short breaks services. The money was allocated to areas incrementally over three years, with the final year allocation totalling £177 million. New growth funding was also included in PCT baseline allocations to enable primary care trusts (PCTs) to work with local authorities to significantly increase the range and number of short breaks. To assist with these developments, £90 million was made available for capital projects supporting short breaks provision.

Increased spending

	2007-2008	2010-2011	Overall % Increase
Total LA and PCT total joint spend on short breaks	£353,191,548	£604,073,285	71%
PCT contribution (including management and supporting infrastructure costs)	£73,839,878	£106,266,854	47%
Total spend (LA and PCT combined on services, excluding management and supporting costs	£321,019,070	£520,895,545	62%

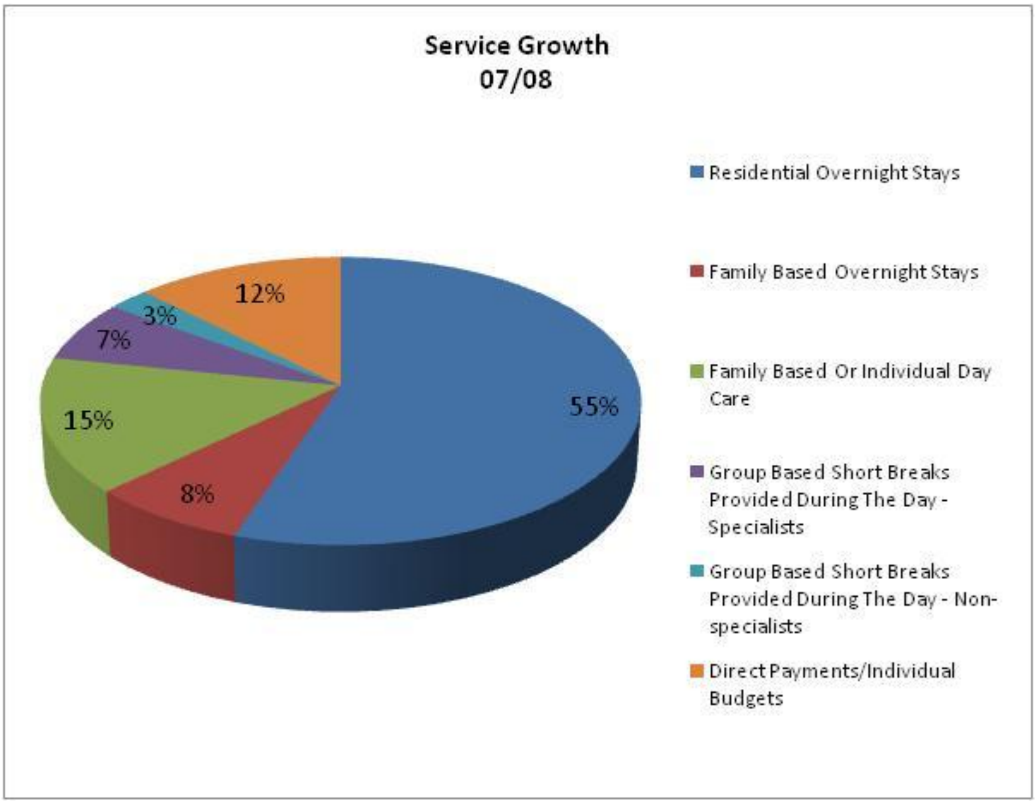
The above table shows that spending on short breaks commissioning has grown in total by over £250 million; an increase of 71%. This includes the cost of managing and administering of services and the costs of participation activity, transport and workforce development; collectively termed „supporting infrastructure costs‟. At baseline, these costs represented 9% of the total joint spend on short breaks and now amount to 14% of the total spend, with 5% on management and 9% on other supporting infrastructure.

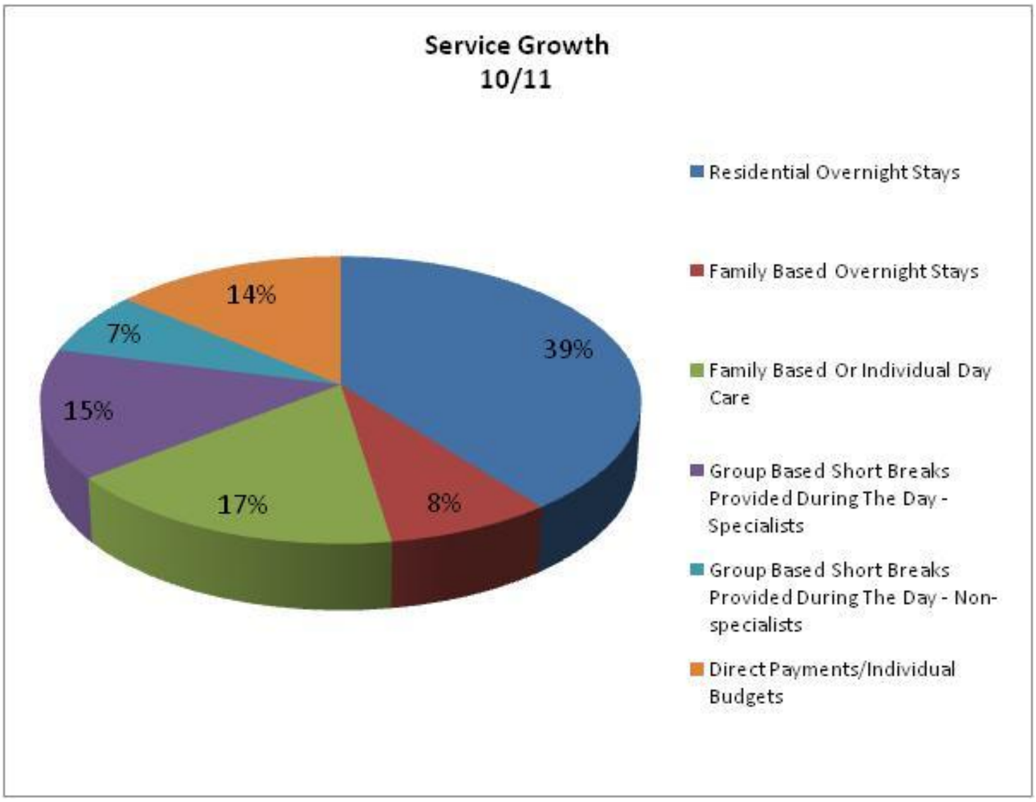
Increases in spend on service models

Service Growth	Baseline	10/11 Spend	Overall increase since baseline
Residential overnight stays	£177,183,380	£205,530,725	16%
Family-based and other models overnight stays	£24,741,662	£42,124,467	70%
Family-based or individually supported day care	£49,023,879	£88,086,692	80%
Group-based short breaks provided during the day – specialists	£21,817,986	£75,824,167	248%
Group-based short breaks provided during the day: non-specialists	£8,092,213	£36,866,049	356%
Direct payments/Individual Budgets	£40,159,950	£72,463,445	80%

The volume of overnight stays has increased by 33% overall. However, there have been different levels of growth across the various models and the increases in spend reflect this. Spending on residential overnight stays has increased by 16%, whereas in family-based and other models overnights, the increase is much more, at 70%. Spending on both models of group-based short breaks has increased hugely: 248% on specialist groups and 356% on non-specialist.

Changes in how money is being spent





The picture of how money is being spent is changing. Well over half of the short breaks budget used to be spent on residential provision. The proportion of money being used on residential overnight stays has now reduced from 54% to 39%. The proportion of spend on family-based and other models of overnight stay remains the same, although spending on this service did increase. The total share of spend on group-based service models, however, has seen a significant increase from 10% to 22% of the total spend.

Costs and value for money

So far, we have shown that the amount of provision has increased, as has the amount of money being spent. However, it is important to explore whether the increased level of service being provided represents good value.

Overnight breaks

The major share of money being spent is on the commissioning of overnight stays, even though the overall percentage share has in fact decreased. The reason for this is obvious, as overnight stays are expensive, typically requiring a paid worker to be on duty over a 24-hour period. Over the course of the programme, spend has increased by 16% on residential overnights and 70% on family-based overnights; a 23% increase overall.

The number of nights has increased by 33% and there has been a 71% increase in the number of children receiving nights. There has been an increase of over 100% in settings such as holiday parks and camping weekends; of 78% in the child"s own home, over 40% in hospices and 28% in family-based settings.

The average cost of overnights (all types) has decreased overall by 8%, from £344 to £317 per night and per child by 28%, from £13,381 to £9,570 per annum. So although more money is being spent on overnights, more children, proportionately, are receiving services that are costing less per child and per unit to deliver, largely as a greater variety of service models are being used and there is less over-reliance on expensive residential unit facilities.

There is considerable local variability in overnight costings, with 77 local areas providing overnights at less than the average cost per night and ten of these areas reporting that costs are less than £150 per night. The variances depend on the range of models being commissioned and the size of the population requiring overnight stays.

Overnight breaks	Baseline	10/11	Increase from baseline
Average number of nights per child	39	30	-9
Average cost per child	£13,381	£9,570	-£3,811
Average cost per night	£344	£317	-£27

Daytime short breaks

Spend on family-based and individually supported breaks has increased by 80%, with 87% more hours being commissioned for 133% more children. This has resulted in the individual overall cost per child decreasing by 23% (from £2,358 to £1, 821) and the cost per hour reducing to £13. Seventy five local areas report a unit cost that is lower than average, with 54 of these areas reporting costs of less than £10 per hour.

Family-based or individual day care	Baseline	10/11	Increase from baseline
Average number of hours per child	170	137	-33
Average cost per child	£2,358	£1,821	-£537
Average cost per hour	£14	£13	-£1

An increased spend of 248% in specialist group based breaks has provided 175% more hours to 246% additional children. This has resulted in an increase in unit costs of £5 per child (from £853 to £858) and £4 per hour per year. Although the unit costs have increased slightly, there is the capacity to provide a service to a far greater number of children with this model, which has the added value of being more flexible and responsive than an individual (support worker or family) can be.

Group-based short breaks provided during the day: specialists	Baseline	10/11	Increase from baseline
Average number of hours per child	74	59	-15
Average cost per child	£853	£858	£5
Average cost per hour	£11	£15	£4

An increased spend of 344% in non-specialised group-based breaks may seem high but still represents the smallest proportion of the overall budget. Even so, this model provides for 45,000 children compared to 26,000 having overnights and the spend on overnights is a 47% share of the total budget. Immediately, value for money can be seen. It is important, however, that the option of overnight short breaks remains in all areas; it is an essential model of provision for many families. Rather, it should be one element of a comprehensive short breaks service. Over two million hours were provided to children for group-based, non-specialist breaks, an increase of 298%, resulting in a unit cost of £822 per child (10% decrease) at the rate of £15 per hour.

Group-based short breaks provided during the day: non-specialists	Baseline	10/11	Increase from baseline
Average number of hours per child	75	55	-20
Average cost per child	£961	£822	-£139
Average cost per hour	£13	£15	£2

Increasing the range and choice of short breaks services available to families of disabled children

Headlines

- Significant growth has been demonstrated across all service models with the types of services being commissioned led by the needs and wants of disabled children and young people and their families
- The shape of market provision is changing significantly in response to the expressed needs of children and families
- More „ordinary life‟ models of provision in universal settings have developed - giving excellent value for money as they are easier to access and give high user satisfaction
- Investment in developing the workforce has been instrumental to increasing the quantity and improving the quality of short breaks and the majority of areas are maximising the skills of parent carers in delivery of training
- Children and young people are increasingly taking a more active role in shaping services and the programme has been a catalyst for change in increasing children‟s participation

Redcar and Cleveland

"Children and young people's views and ideas led to the design of the types of activities offered in short breaks settings. Data and LAIMP projections gave us the information we needed to project indicative hours. As a result, we have commissioned a range of services to meet all needs identified at that time. This of course would need to be reviewed regularly according to the local area‟s commissioning principles. We feel that we have provision right - we are „just about there' - with providers."

Overnight short breaks by service models	**Actual 07/08**	**Actual 10/11**	**Overall increase**
Total number of disabled children who receive overnight breaks	15,090	25,878	71%
Overnight stays (nights)			
Number of nights in residential units	377,391	451,070	20%
Number of nights in hospices	32,971	46,797	42%
Number of nights in „other‟ settings (includes: adventure holidays, camping weekends, youth-club residential etc)	25,397	57,151	125%
Number of nights in family-based settings	87,494	112,096	28%
Number of nights in child's own home	63,842	113,713	78%
Total number of overnight stays	**587,095**	**780,827**	**33%**

Overall, nights have increased by 33% and 71% more children are accessing at least one model of overnight stay. However, within the range of models available there have been greater increases in more innovative models of provision, such as weekend residential trips with youth clubs. This has changed the shaped of the proportions of provision.

Working in partnership with the health sector

The AHDC programme was jointly financed and delivered by the Department of Health and the Department for Education. Although local authorities were the lead agency at locality level, the expectation was that they would work in partnership with their corresponding primary care trust (PCT) to plan and commission short breaks services. Generally, there was a positive response from the health sector to address the needs of disabled children and there are some excellent examples of partnership working in evidence throughout the report and more in the TDC product *„Developing effective joint working between health and local authorities‟.*

However, in some areas it has been a challenge to understand the health contribution to short breaks delivery. Several areas could not identify PCT financial contribution, although health spend nationally did increase by 47%. also In part, the challenge to demonstrate health input was made more difficult as the budget was often spread across services and difficult to disaggregate (for example, health sector spend on therapist input).

There certainly is more evidence now of a greater level of partnership working, that is demonstrated in shared visions and objectives, shared understanding joint posts, pooled budgets, joint workforce development programmes, specialist service provision and provision of aids and equipment.

Norfolk runs „Short Breaks Plus", which caters for children with additional and complex needs. Carers receive specialist training and are carefully matched with children. *"We take great pride in matching the right carers to the right children. The key to a successful short break is that the child, the parent and the carer [are all] happy. All [our carers] make their homes friendly, safe and welcoming for children to stay in. Disabled children can go to other houses like a sleepover that their siblings may already experience."*

Suffolk runs „Forest Festival" as part of the „Other" type of overnights provision. This is a residential camp where activities are run over the school holiday periods. Children of all levels of disability are enabled to attend.
"For those youngsters with additional needs, the camaraderie is palpable. It is clear that everyone in the group was being encouraged to „give it a go". Carers, peers and volunteers all encouraged one another. I witnessed inclusion at its best. Being away from home builds independence in a safe, supported environment. For my son, new avenues have been opened and he has a whole new list of Facebook friends!"
Parent

Nottinghamshire offers „Enhanced Breaks" – a scheme that enables families to take up the option of having a supported holiday as a family instead of their child having a longer break away from home while they holiday separately. Fourteen families took up this option last summer. Paid carers accompany the family to ensure that main carer has a complete break from their caring responsibilities.

One family says, *"It was great to get away as a family … and have two carers with me. It was delightful to see my girls enjoying things together and granddad, at 70, had the best holiday ever!"*

Ordinary life and value for money

Children in the majority of families will spend nights away from home as part of the normal course of growing up. Using a model of service that gives an overnight break from caring and yet is not the traditional residential model really does mean that families can feel that ordinary life does not have to be further compromised and can only enhance family cohesion. The model of all the family going away, but with additional support provided so that the main carer can have a break, is a real innovation and boosts the resilience of the family unit.

The average cost of an overnight stay in a residential model is approximately £472 per night. The cost of other types of overnights including family-based models, camping or holidays is £127 per night – less than a third of the cost of a residential night. Clearly, residential units need to remain an option for families who need or want that provision. However, the additional funding has allowed authorities to experiment with a whole range of overnight models and they have found that these give high levels of satisfaction as well as being very cost-effective and therefore representing greater value for money.

"I can't believe just how easy it was to take K away with us. To think I used to leave her in a unit – it broke my heart to leave her behind. S, (the support worker) became just like a family member and it made the differences between K and our other kids seem so much less. This has got to be an option for all families."

Family-based and individually supported short breaks in the daytime

Portsmouth

"The buddying and befriending scheme has enabled families to start accessing more universal services with the additional support available when necessary ensuring choice and flexibility when accessing a service."

Family-based or individual day care/ sessional provision (hours)	**Actual 07/08**	**Actual 10/11**	**Overall increase**
Total number of disabled children receiving these short breaks	20,788	48,370	133%
Number of hours in salaried, contract carers or linked carer's homes (in the carer's home)	420,800	758,962	80%
Number of hours in care in the child‟s home (sitters or personal assistants)	1,330,042	2,327,361	75%
Number of hours provided to support children to have breaks by personal assistants/outreach workers who take the child out of their home, on an individually supported break	1,596,221	2,920,068	83%
Number of hours in „other‟ (includes daytime breaks given in residential units and resource centres)	195,236	609,164	184%
Total number of hours	**3,542,299**	**6,616,164**	**87%**

Generally, the increases across the range of types within this model have been similar but the number of hours in the „Other‟ category has had a significantly higher increase than others. This category includes any other setting where the child receives an individually supported break and has occurred most frequently where residential units have expanded their provision to offer breaks during the day instead of the child needing to stay overnight. This has been particularly helpful to the parents who said that they often only used overnights, as evenings were the most stressful points of their day. An evening‟s break, where the child returns shortly before bedtime, provides a break without the child having to be away overnight and is, of course, far less costly.

The pattern of provision has only changed slightly over the last three years, with a greater proportion of hours being delivered in other settings. However, the greatest number of hours given in this model remains with personal support workers/outreach workers. The proportion of hours given in contract carer settings has remained the same although having increased by 80%. Many authorities expected to achieve greater increases in this type of provision but experienced challenges. These are explored at length in our report *'Impact of Aiming High for Disabled Children on the Development of Family Based Short Breaks*.'

"So much more than a break for me!"
B is 16, lives in **Derbyshire** and his severe autism has led to a very restricted lifestyle and being dependent on his family, meaning that they are under considerable stress. They have found it difficult to trust others to care for B, because of his ritualistic and bizarre behaviour. A specialist support worker was recruited through the short breaks programme and linked to B because of their shared passion for motorcars. Much of his short break time is spent in scrapyards and under vehicles engaged in an activity that he clearly loves! A more confident and calmer B and his outreach worker are building a car together and his family are delighted with the outcomes.

Group-based specialist short breaks

Group-based short breaks provided during the day: specialists (hours)	**Actual 07/08**	**Actual 10/11**	**Overall increase**
Group-based services: specialist provision			
Total number of disabled children receiving group-based specialist services	25,589	88,419	246%
Number of hours in extended school provision	236,605	919,712	289%
Number of hours in youth work provision	303,312	876,247	189%
Number of hours in Saturday or Sunday schemes	308,125	850,164	176%
Number of hours in School Holiday schemes	846,101	1,727,244	104%
Number of hours in children's centres	46,988	201,817	330%
Number of hours in other (specify)	161,725	649,496	302%
Total number of hours of group based specialist provision	**1,902,856**	**5,224,680**	**175%**

Increases in group-based specialist services have been excellent and, again, there has been considerable variation in the growth of different service types. The greatest proportion of hours has historically been given during school holidays and this remains so. However, although growth has indeed been substantial (104%), it has actually seen the smallest rate of growth and increases in children"s centres (330%), in other settings (302%), extended services in schools (289%), youth work (189%) and weekend schemes (176%) have all been more significant, changing the shape of market provision.

Gloucestershire runs cookery schools for children with autism during school holidays as part of their group provision. They are thrilled to have the involvement of a Michelin starred TV chef as part of the attraction!

The changes in service models reflect the need expressed by families to have regular, reliable breaks where children can learn new skills and enjoy the types of activities that all children engage in when they are not at school. Activities in school holidays are very much needed and valued, but breaks at weekends have a much more „normal‟ feel as most children will go off to dancing classes, sports activities and so on. Indeed, weekend activity sessions are a rapidly developing model of service, being offered in some very innovative ways. They are hugely popular and clearly fulfilling a real need.

Quote from letter from parent of child in Kent

"Our day at the museum was absolutely fabulous. C was louder on the way home and had we had to travel on the tube with people who didn‟t know him our day would have been unbearable. I pray that we will be able to access this sort of thing in the future. Please make sure that everybody realises how much they are needed and appreciated."

Again, a model of involving the whole family in activities is being seen in some authorities. Parent carers are given the choice to go along on group outings in some areas, along with other siblings. They are not expected to have the responsibility for caring but it allows the family to have a sense of „doing something together‟ and is also useful when the disabled child is much younger and not used to being left as it enables confidence in workers to be developed over time. Parent carers can then withdraw at their own pace as their confidence increases.

Havering

At the progress review parents present said that they were very happy with the volume and range of services now on offer. A pilot scheme for teenagers is now in place giving £25 per month on a Leisure Options Card to encourage teenagers with disabilities to take part in activities. This is proving to be popular and may be expanded. Our universal services have also been pro-active with Leisure services now providing a range of activities - the swim and gym scheme is funded through our short breaks programme.

Group-based, non-specialist short breaks

Group-based short breaks provided during the day through non-specialist provision: universal (hours)	**Actual 07/08**	**Actual 10/11**	**Overall increase**
Total number of disabled children receiving group-based non-specialist services	8,419	44,988	433%
Number of hours in extended school provision	138,602	446,706	222%
Number of hours in youth work provision	77,358	364,555	371%
Number of hours in Saturday or Sunday schemes	19,457	159,981	722%
Number of hours in school holiday schemes	240,504	571,120	137%
Number of hours in children's centres	93,512	446,699	378%
Number of hours in other settings	65,093	478,378	635%
Total number of provision hours	**634,526**	**2,467,439**	**289%**

Increases in this model of provision have been the greatest of all at 289% and more. Weekend schemes used to account for only 3% of market share and this has doubled to 7%, having increased by 722% overall. Share of hours for school holiday schemes has decreased to 23%, the smallest of all increases although still considerable at 137%. However, it is in children‟s centres that the greatest change in share has been seen and this type of break now accounts for 18% of the provision of hours. What this analysis tells us is that more breaks are being provided in universal settings throughout the year rather than peaking in school holidays. This again reflects the needs of families to have access to ordinary life models.

Southwark

"We have worked very hard to forge links with universal service providers and we now have a good range of services in place for disabled children. These will continue post March 2011. This is also the case with Youth Services who also provide services for disabled youngsters and, again, we are hopeful that this has embedded and will continue. We have also run a workshop with professionals and parents and we are hopeful that lessons learned will help us to continue to provide some sustainable services post 2011, although there is clear concern from all regarding budgetary pressures."

Another factor is that the increases in children‟s centre settings reflect a need from families to have earlier access to ordinary life models. Children‟s centres are universally available and locally based so easier to use and do not pose the usual transport issues that often arise when trying to reach a specialist setting. These centres are generally within walking distance of homes making them much easier to access and also offer support mechanisms from the parents of other children. The availability of breaks in a universal setting to much younger children has been a strategy of many of the high-performing local areas, who have intentionally used short breaks as an early intervention, lessening the likelihood of pressure on families building over time. The strategy has a multifold purpose as it puts parents in touch with professionals for advice and guidance, enables them to meet other families for peer support and offers inclusive provision from an early age. Breaks in such settings offer value for money as they cost less to provide and have a positive impact overall, giving families satisfaction early on in the process.

Development of the workforce

A key issue in increasing the number of breaks available and improving quality has been addressing the skills of the workforce. High-performing local areas have talked about this as being crucial to the development of short breaks commissioning and have invested considerable resource in this.

Warwickshire

“We capacity build on an ongoing basis, thereby building skills in our mainstream workforce. We listen to providers and offer training to meet the individual needs of children attending settings and schools.”

Sunderland

“ The Quest service, which works with children with severe learning disability and severely challenging behaviour, has delivered 'managing challenging behaviour' training to one of our commissioned services, which has enabled them to work with young people who previously would have been considered too challenging.”

Durham

“Workforce development has supported the increase in volume and range of short breaks services and providers are better equipped and skilled.”

Involvement of parents in training the workforce

Parents are a rich resource for training, having built up a wealth of skills from their own experience of caring. Almost two thirds of local areas are using parent carers as part of their delivery of training.

York also support Early Support Training programme and parents are co-trainers of the 'Parent Workshop and Working in Partnership' course. Recently the audience targeted has been extended beyond early years to include those working with all ages. Parents and professionals promote the training across the services.

Waltham Forest

"The Parent Forum has used some of the additional funding from Aiming High for Disabled Children to run training events for parents. We are currently looking at a proposal to fund a „Sleep Solutions" project, which will include training parents to become counsellors and support workers."

Local authority officer

Darlington

"Parents have recently had the experience of delivering training to special needs coordinators and hope to build on this. Parents are about to undertake a basic teaching qualification to enable them to facilitate training sessions for members of the workforce and this is being linked to the children's services workforce development team."

Local authority officer

See appendix I - charts and tables of growth in range of services.

Involvement of disabled children and young people in shaping services

A research study carried out by TDC in November 2010 reported that the AHDC programme has been a catalyst for change and provided a focus for the participation of disabled children and young people across all areas of service development. It has led to a large increase in the number of disabled children and young people being involved in commissioning.

Durham's „Extreme" Participation Group" has been involved in a number of projects, including helping to shape a range of imaginative short break activities. Their own words sum up their aims: *"We aim to improve service so that other young people don"t have to experience the difficulties we have sometimes experienced. We support each other as a group, we listen to other people"s opinions, we grow in confidence ourselves and work to challenge policies, services and people"s perceptions."*

As a direct result of disabled children and young people"s participation, a wider range of universal sporting and leisure activities has been commissioned.

In response to AHDC, **Knowsley** decided to work with universal services and use their established engagement systems to listen to the views of disabled children and young people. They brought together a group of disabled children and young people to act as „Young Inspectors", identifying services to inspect and draw up conclusions and recommendations from their findings. As a direct result, the local authority has been able to develop services that meet the specific needs of these children and young people, targeting funding towards a growth in universal services.

As a direct result of the AHDC funding, **Swindon Borough Council** established „Chatterboxes‟, a group for disabled children and young people to come together and be actively involved and consulted with about all services that affect them. The group was asked by the local Safeguarding Children Board to gather information on the level of disabled children and young peoples‟ understanding of safeguarding. A consequence of their findings has highlighted the need to strengthen service providers‟ access to disabled child protection training, especially in the short breaks field, and has reinforced the need to address disabled children and young people‟s awareness and understanding of neglect and sexual abuse.

Prior to AHDC, 40% of the sample had not enabled disabled children and young people to participate in service development.

"The resources have never been available before, we never had the time or the skilled staff to carry out this work."

Local authority officer

There were few respondents who were confident about their ability to continue with their participation work beyond the life of the AHDC programme.

Hounslow Borough Council commissioned a theatre project with the Chicken Shed Theatre Company. There were five sessions arranged with disabled children and young people from both specialist and mainstream schools coming together to put on a production. The theme was „How would I change things?"

Throughout the duration of the AHDC programme we have seen a significant increase in the numbers of disabled children and young people who are involved in participation and the majority of areas now report that they routinely involve young people in service planning with 59% stating that more than 10 young people are involved regularly in the decision making processes around service development.

Local areas continue to report difficulties in engaging effectively with disabled children and young people from black and minority ethnic groups.

Moving forward

The range of short breaks has increased hugely with many more types of activity-based breaks being available to families. Many local areas are now offering easier to access models and by developing partnerships with universal service providers and investing in developing the workforce, are able to offer breaks that fit an „ordinary life" model, increasing family resilience and user satisfaction, thereby giving excellent value for money. Easy access models also have the potential to facilitate peer support and ease the pressure of caring at a much earlier stage. Market provision is changing shape, being led by the expressed needs of parents and children who are becoming more actively involved in decision-making processes around planning services.

There are ongoing challenges, particularly as the uncertainty of funding universal services such as youth work provision begins to have an impact. In many areas, as the programme draws to an end, short breaks leads officers have been made redundant and there is no longer a named person responsible for their continuing development. This will be a real issue going forward. However, for parents and children who have seen what is possible and the positive impact it can have on their lives, there can be „no going back".

"*Believe me, life before Aiming High was grim - two nights a month in a unit – and I hated her going there. Now, we have services that we actually want, they cost less and she is so much happier – and she is learning more and growing in confidence. It would be madness to stop this. Whose purposes will that serve? No, there is no going back."*

Quote from a parent

Development of provision for disabled children with complex needs

Headlines

- Over 73,000 more children with the severest level of needs are now receiving short breaks – an increase of over 200%
- Partnership with other stakeholders, particularly parent carers, has been a major factor in the successful development of services for children with complex needs.
- Significant cost savings have been reported by areas that have invested in increasing the volume and range of services available to children with very complex needs
- More opportunities are available to enable the most severely disabled children to take part in „ordinary life" activities

> *"I have friends who have children with complex needs who wouldn't let their children out of their sight before Aiming High came along. The impact of this programme has been huge."*
>
> Parent of a child with complex health needs

Priority groups

Historically, disabled children with the severest needs have been less able to access services, largely because of the challenges that their disability poses for providers.

Two particular groups of children were most affected: those who had severe challenging behaviour (often also affected by an autistic spectrum disorder) and those who had complex health needs[11]. Throughout the programme, these children have been termed as being in the priority groups[12].

The short breaks transformation programme aimed to address this issue by encouraging local areas to target children in priority groups by commissioning a comprehensive range of services based on consultation with the children and their families. Furthermore, the Full Service Offer made it explicit that the priority groups of children should be able to access the full range of short breaks and authorities should work towards greater equity across the board.

The majority of local areas have demonstrated improved access and significantly increased the level of provision for children in these groups. There are still issues to be resolved in some areas and challenges going forward.

Establishing a baseline

The establishment of a robust and reliable baseline has been a challenge for local areas from the outset of the programme. Many found it difficult to provide data about numbers of children using short breaks and, in particular, about the children who would fall into the priority groups. TDC worked with areas to support them in tracking back through provider lists of children or by talking to parents, carers and providers in order to make their baseline data more robust and meaningful. Data collection improved hugely across the country. Despite this, 51 local areas remained unable to accurately determine a reliable baseline number for children in the priority groups and have therefore only been able to reliably measure growth in these groups since 2009/10.

Growth in services for children in the priority groups

> *"Thank you! To return to the old days would be dire indeed."*
>
> Quote from a parent

Using these 101 local areas as a sample group, there has been a reported increase of 178% in the number of children with challenging behaviour and/or autistic spectrum disorders and 166% in the number of children with complex health needs receiving short breaks since baseline. This compares with a 201% increase in the numbers of all disabled children having short breaks in the same sample group.

Models of service and priority groups

Local areas have been better able to establish baseline numbers for the individual models of provision. This is largely due to individual providers knowing the children using particular services and their level of need.

Increases have been reported in the proportion of children in priority groups as a percentage of the total number of children having each type of short break and in the number of nights/hours being received by those children.

Factors of success in the development of services for children with the severest level of need

The following factors of success have been drawn from analysis of learning and informed through structured interviews with a number of areas evidencing positive outcomes in this area.[13]

Partnership and participation

Involving key stakeholders (especially parent carers and young people) to identify needs and aspirations has been essential. These consultations and an ongoing dialogue highlighted the need for an approach that facilitated an „ordinary-life" model. The aim had to be that children, no matter what their level of disability, had access to fun activities that their peers were able to enjoy. Parents and young people were therefore integral to the planning, commissioning and evaluation of services.

Dudley commissioned Mencap to consult with young people and families who subsequently became part of the commissioning panel assessing tendering bids.

Partnership working between statutory and voluntary organisations has been enhanced where there has been pooling or aligning of budgets or where there are fully integrated multidisciplinary teams.

Robust mapping of needs

Demographic/local population data was analysed systematically and jointly with health partners to identify patterns and trends to inform strategic planning. This included collection and analysis of baseline data on provision for disabled children. There was also a commitment to good ongoing data collection to measure growth. Gaps were identified with regard to the specific priority groups.

Durham identified that children on the autistic spectrum who also had challenging behaviour were over represented in out-of-area residential schools. They therefore targeted this group for short breaks packages. They have estimated that they have prevented 35 such children from being placed out of the area or entering the looked-after system.

Strategic and targeted planning

A common theme has been use of short breaks as a preventative strategy with the aim of keeping the children within their home and community and preventing children from entering the looked-after system. Systematic targeting of children in both priority groups was undertaken and services were specially commissioned to meet their needs. Some areas included case studies of disabled children in the priority groups in all their published tenders.

Outcomes-based commissioning encouraged local commissioners and providers to be more child and family focused and more creative. As a result, children were able to access some exciting and innovative services, no matter what their level of impairment.

"*This year we had the best summer ever. E did something different most days in the holidays. She went to the cinema, did cooking (with help), and went with her new friends to a special adventure playground. Our whole family had a four-day holiday in a house by the sea – our first all together. We had such fun and all laughed a lot.*"

Brother of a disabled child

Capacity building and workforce development

Working in partnership to upskill workers and increase their confidence, and that of parents and children, has been essential. Continuing staff development was offered to all providers. This included staff being able to access local authority and health service training and have access in many areas to specialist professionals.

Building on existing services

Not all services needed to be newly commissioned. There are excellent examples of local areas looking at what already works and building on that.

In **North Tyneside**, the short breaks residential unit was developed so that it could be divided into two self-contained sections to enable children with different needs to be accommodated on the same dates and an additional bed provided for assessment.

In **Newham**, the residential unit there also became a drop-in day centre for parents and children.

Contract carers were recruited from existing family link carers, thus reducing the time needed for assessment and preparation. This meant that they could start providing the service more quickly.

Nottinghamshire has recruited ten contract carers who are providing a service to 70 children in both priority groups and this has been developed within two years.

Information and signposting

Good quality information for parents, young people and professionals on what was available was key to the promotion and usage of the service. Several types of media were used such as regular newsletters, working closely with the local Families Information Service, parent forum events with marketplace opportunities for providers, and the use of coordinators to broker services that parents and young people needed with providers. This included giving support to providers to meet the specific needs of the child. Staff training included learning about available services so that there was effective signposting. Close partnership working with parent forums has been important to make sure that word of mouth methods were maximised.

Open access frameworks

Easy and timely access to services is vital. A tiered framework, where the first tier of services is universally available with no assessment needed, has been the most effective and received the best feedback from parents. The effect has been twofold; children with fewer complex needs access services in the first two tiers so that formal assessment resources can be focused on those with more complex needs.

Additionally, in many cases, children in the priority groups could also begin to use other open access services immediately whilst assessment was ongoing.

> *"Parents told us that they could not believe the ease of accessing services for their children. They thought it was a con and did not do it until other parents told them about the scheme."*
> LA short breaks lead.

Illustrations of service developments for children with challenging behaviour

Plymouth targeted young people with a diagnosis of Autistic Spectrum Disorder; often the young people who could not access mainstream activities due to the background noise and busy atmosphere. They organised small groups, staffed by those with specialist skills, who supported young people to attend holiday activities such as sport, drama or music.

Durham has used a stepped approach to address the issue with children on the autistic spectrum who also have challenging behaviour. The North East Autistic Society was commissioned to provide a menu of support that included bespoke packages, crisis intervention, short breaks and training for families and professionals.

Sunderland worked in partnership with the psychology service and targeted young people with challenging behaviour and severe learning difficulty. The staff providing this service (Quest) conduct an assessment and develop a behaviour management plan for families and professionals to implement. They also offer ongoing supervision. The plan focuses on recognising triggers, de-escalating situations and reducing physical restraints. This has an impact on the young people‟s ability to access universal services.

Complex health needs

Warwickshire has developed a 'sit at home or out-and-about service‟ by investing in the NHS community children's nursing team who provide supervision and ongoing training to support workers. Two healthcare assistants were recruited to offer a short break to those with the most complex/medical needs.

Lambeth has worked closely with the local school for children with complex health needs to enable them to offer an extended curriculum through school sports partnerships. This included a three-week play scheme during the school holiday. Siblings were also able to attend.

Dudley and **Walsall** have targeted children and young people with complex health needs and life-threatening conditions to receive palliative care at home through Hospice at Home pilots.

Bolton has extended the use of one of the children‟s centres to meet the needs of young people with physical disabilities and substantial moving and handling needs. They now work in partnership with the local area play services department to provide holiday support for young people with complex health care needs.

Capital investment to extend services to children in priority groups

Dudley has used its capital funding to provide specialist equipment and change beds for all youth centres in the borough.

Newham worked with a housing association to remodel the garden in a child‟s home. The design gave him a space he could go to that was sympathetic to his individual needs as a child on the autistic spectrum. It provided the opportunity for him to „chill out‟ thus giving his parents a short break at home.

Listening to parents

Parents have also shared their experiences of initial and ongoing consultation that resulted in their local areas developing solutions that led to savings in costs.

"It was truly a participative process – they‟ve actually started to listen!"

Families strengthened

Parents talk about the way they have been helped to cope better and be kept together. Some parents have been confident enough to access or remain in work.

"Families have been able to go away together, accompanied by a support worker who can look after the disabled person, giving both them and the family quality time to enjoy their individual chosen activities. A win-win situation for everyone."

"For me it means I can work and I am more relaxed. When I split from [father of children] although I was devastated I knew that with the support of short breaks, I could continue to care for all my children alone."

Enjoying seeing children having fun

A normal part of parenthood is watching your children grow, develop and enjoy themselves. With disabled children, this „taken-for-granted" experience has not been commonplace. Many parents talk of their delight in simply watching their own child enjoy an activity.

"B has never been to the cinema before. He went today and saw Toy Story. He was able to describe to me with a smile on his face and his hands that he had seen it on a big screen - the first time he had ever been able to tell me about an activity he had enjoyed."

"My daughter has lots more fun with age appropriate activities. She mixes with her peer group and is making friends. Her life is much more „normal". My daughter has now started to engage with people outside her family."

Parents, children and young people have increased confidence in accessing new environments and a decreased feeling of isolation both for themselves and their children.

> *"It has been very positive for sibling groups to have positive activity opportunities with their disabled sibling and our disabled son is less isolated and has the opportunity to meet other children."*

Better outcomes for service planning

The active involvement of children, young people and parents in deciding what services needed to be developed and then being part of the commissioning process was a culture change for many areas. Joint planning has been found to be cost-effective simply because the services that are developed are ones in which parent carers have a shared ownership and are committed to making work. Take-up is better and greater use of resources is reported.

Significant cost savings have been seen in local areas that have targeted children with the most severe needs. These are the children that are most likely to need long-term care as the strain on families can be so much greater. Investing in short breaks as an early intervention strategy and developing a wrap-around package, giving high levels of support based in the home at times when pressure is at its peak, has led to families being able to cope better and increased their resilience. Thus the strategy has prevented children from entering the looked-after system. A decrease in requests for emergency placements was also reported.

> *"We saved a lot of money! We were surprised and able to jointly plan more services requested by children."*
>
> Local authority commissioner

In **North Lincolnshire,** health professionals, including a community paediatrician, have worked collaboratively to ensure staff in Cygnets (short breaks unit) are better equipped and able to carry out invasive procedures with children with very complex health needs to enable them to benefit from a break in the unit.

Moving forward

Parents feel there has been significant progress but there clearly remain challenges to overcome. Not all parents are finding information easily available and families in black and minority ethnic groups are not always represented on parent carer groups. Workforce development is still embryonic and will need continued investment. Given the enormous challenges around finances in all local authorities, there is the danger that staff training will be an early casualty and thus momentum in engaging the universal sector in short breaks provision will be lost.

There have been significant increases in the number of children with more complex needs accessing short breaks. Access has become easier in most areas. Local areas have shown commitment to the further development of services for children in these groups, in particular to continue widening access to universal services.

Local areas have approached the development in a variety of ways. Central to this has been listening to the views of, and working in partnership with, parent carers and other major stakeholders. A strategic process based on a robust analysis of need was also crucial to success in developing services for these groups of children.

A good range of services has been commissioned that are flexible at the point of delivery. These projects support the rights of disabled children with the most severe disabilities to have the same opportunities for fun experiences as their non-disabled peers and lead ordinary lives.

A commitment to improve data collection and analysis and determine robust and reliable baselines to inform commissioning of targeted services has been demonstrated. Two-thirds of local authorities were able to demonstrate growth from baseline. Qualitative data, collected from parent feedback and evaluations from children, has shown that the development of short breaks services has made a real difference to the lives of many more children and families. There have been demonstrable positive outcomes for parents, children and services.

Direct payments and individual budgets – personalisation of short breaks provision

Headlines

- Personalisation of short breaks is being seen in service development, with a demonstrable commitment to active participation of disabled children and their families
- The families of more than 20,000 children are receiving a direct payment as part of their short breaks package (an increase of 83%) and almost 3,000 families are in receipt of some model of individual budget – an increase of 184%
- Families have welcomed the flexibility, choice and increased control that the move to personalisation has brought

> *"I used to feel as if I was banging my head on a brick wall [asking for help]. I was so exhausted and my life was no longer my own. I turned into a screaming harridan, just to get a break. This system [professional-held personalised budget] has been the very best thing. I honestly think it has saved my sanity. We know what we‟re entitled to, we got to know our key worker really well and she understands because she knows us, she listens. Now we get this budget but we don‟t need to mess with banks and paying people ourselves. J is happy because she is getting out often doing fun stuff with friends and we‟re happy – we‟ve got our life back!"*

Climate of personalisation

Personalisation is an approach where the overall aim is to give choice and increased control back to individual users of services. Implicit in the concept is the premise that users are active participants and need to have control over the resources that are allocated to them and the way in which they are delivered. In recent years, there has been an increased government steer towards personalisation through both legislation and policy and the highlighting of models of good practice.

A comprehensive short breaks service should be one that enables families to have some control over their lives as well as providing a range of choices. From the outset of the programme, local authorities were encouraged to be proactive in supporting the market to ensure that sufficient provision was developed to meet independent demand and open up the market for new providers. This was in addition to strengthening support to current providers as part of the drive to increase personalisation of services through transformed commissioning.

Increases in direct payments

Personalisation has been developed in local areas through the mechanisms of direct payments, individual budgets, personalised budgets held by lead professionals and brokerage support service systems. Significant increases have been reported. At the beginning of 2007-2008 the families of around 11,000 children were receiving direct payments to purchase short breaks[14]. By the end of 2010/11 this figure has increased to 20,714 children in total; an increase of 83%.

	Baseline year	2010-2011	% Increase
Total number of direct payments	11,333	20,714	83%
Average payment per family	£3,243	£3,058	-6%
Total revenue spent on direct payments and individual budgets by local areas	£41,159,950	£72,089,649	80%

Table showing increases in number of direct payments

All local authorities now provide direct payments, and all have reported increases, with ninety-three authorities increasing numbers of recipients by more than 50%. Six authorities have increased their numbers by more than 300%, with one of these increasing from a baseline of 45 to 900.

The average payment per family for either a direct payment or as part of an Individual budget[15] has decreased slightly since 2007/08. This is to be expected given the very large increases in numbers using these models. In many areas, direct payments are now part of a mixed economy of provision to families, who might also be able to make use of a wider range of open-access universal services.

The total revenue being used by authorities has increased from £40 million to over £72 million; an overall increase of 80%. The proportion of total revenue being used on direct payments/individual budgets has increased marginally, from 14% to 15% in 2010/11.

> *"I use my direct payments to employ R as a personal assistant. She knew C well and is more like a big sister to her - they do girly things together, the same as other girls of that age do – go shopping, try on clothes, mess about with make-up and meet up with other teenagers for coffee. C loves it, she sees it as just „hanging out‟ with a friend and I can plan around this regular break. We can decide between ourselves when is best and it‟s good knowing that she is safe and happy."*
>
> R, 17, was a friend of the family and used to babysit for C, who is aged 12 and has quadriplegia and severe learning difficulties.

Individual budgets

As a parallel piece of work to the short breaks programme, the Department for Children, Schools and Families (DCSF)[16] had commissioned a pilot project (with six authorities) to explore the use of individual budgets in disabled children‟s services with the intention of rolling out the learning from that to other areas[17]. Many areas that were not part of the pilot also reported using individual budgets. Some of these were in authorities where the personalisation agenda in adult social care was very strong. Several areas were part of the „Taking Control‟ programme offered by the organisation „In Control‟[18].

In 2010/11, 52 areas reported that they had delivered individual budgets as part of their short breaks offer. This was an increase from nine areas at baseline and included the ten areas in the pilot. A significant regional variation was seen, with areas in the north of England and London being more likely to offer individual budgets.

Reported figures indicate that 2,984 children received an individual budget in the year ending 2010/11; an overall increase of 184% since 2007-2008[19].

Investigation into how authorities outside the pilot study were delivering individual budgets indicated that there was considerable variation in definitions and approaches. Most of these areas have offered this approach as a local pilot and were shaping the process as they added to their learning. Generally, authorities wanted to offer a more personalised approach, widening the options available to families, and had used some of the additional short breaks funding to progress the personalisation programme in their areas. Some of these areas had published definitions that were available to families and young people, one with an extensive web-based resource and guideline pack. Others were in the very early stages of progressing this agenda and were developing definitions as part of the process. Clearly, there is considerable variation in what local authorities are terming „individual budgets‟ and most seem to be using the category in its broadest sense to capture how funding is being used to offer a range of personalised budget models.

Difference between a direct payment and individual budget

The majority of areas were clear that a cash direct payment was essentially one possible element of an individualised budget approach. Some areas are more specific in their delineation and only use individual budgets in situations where funding is drawn from different streams.

Eligibility criteria used for Individual budgets

Half of the authorities have robust and clear criteria for individual budget eligibility that include published processes and/or local offers for accessing individual budgets if the family meets particular social care thresholds. Other areas targeted families or young people at specific stages of their lives, such as those in transition to adult services. Two areas report that they kept the eligibility criteria deliberately flexible because of the small-scale nature of their individual budget.

Many areas introduced individual budgets solely as an easy access model – offering families the opportunity to access small grants to enable family holidays. This may have inflated the amount of packages available during the course of the programme and is not likely to be sustainable in the longer-term.

Individual budgets, as one of the mechanisms for progressing personalisation, offer flexibility and choice to families who otherwise might not benefit from short breaks. Across the board, positive impacts and outcomes for families and services have been reported including higher levels of parental satisfaction, greater family empowerment and improved relationships with services. However, this stage of early development of individual budgets means that most areas have not completed any formal evaluation or cost analysis.

Success factors in developing personalisation through use of direct payments[20] or individual budgets[21].

Commitment to the ethos of personalisation – There was a shared vision around achieving greater choice and control: the principles underpinning personalisation. This included a demonstrable commitment to shift the balance of control from the authority to the family.

Understanding need and demand – Market availability was systematically reviewed and areas worked closely with parents to find out more about what they wanted from providers. Generally the aim was to be better informed to increase effectiveness in commissioning, develop the market and improve quality so that there would be sufficient supply of quality services and increased choice.

Acknowledgement of historical reluctance –There had to be honesty about the reluctance of some personnel in social care teams to devolve choice and responsibility to parents/carers and an acknowledgment that this has resulted in low numbers of families being offered direct payments in some areas.

Developing confidence – Workers and parents needed to increase their confidence in how things would work. Areas committed to shift to a „child and family centred-approach‟, with an emphasis on „family support plans‟.

Partnering with parents - Participation with parents has meant that authorities have known from the start the types of providers‟ services that needed to be expanded and, consequently, where the investment needed to be. They were also clearer about the type of support parents needed as they listened to the anxieties that some parents had and were able to facilitate the sharing of experiences. Partnering also meant that providers needed to listen to how important it was that children and parents were able to exercise control and have real choices.

Some of the parents in **Darlington** wanted to use their direct payments for holidays to enable the main carer to have a break whilst keeping the family together. The system militated against this as payments were issued monthly. However, the local authority responded by making an initial payment equivalent to five months‟ allocation. This simple change has given parents far greater flexibility and the capacity to plan ahead.

A Short Breaks Allowance System was introduced in the **Wirral** in 2010 as part of their local offer. This is an open access payment for those families receiving a higher rate Disability Living Allowance, but not eligible for specialist services. The payment is equivalent to £15 per week and enables the child or young person to access everyday activities like judo or karate. Indeed, one young person purchased a trombone, enabling them to become a member of a band!

Sutton has introduced care packages involving a mixed economy with parents being able to access both commissioned services and directly purchased services with their direct payments.

Since April 2010, **Nottinghamshire** has developed two types of direct payments for short breaks.

The „100 hours scheme‟ can be accessed by parents as part of a local access offer. Parents can use a pool of providers (commissioned by the authority specially) to purchase their personal support. The providers are paid directly by parents.

Those young people with more complex needs (determined by assessment) can receive a direct payment as part of a mixed economy package. Direct payments are flexible at the point of delivery and can be used for personal assistants as well as to purchase hours in activity-based groups.

Practical support for parents – In some areas, the local authority initiates the direct payment by developing the agreement, opening bank accounts and completing Criminal Reference Board checks. Support for employment related issues is then handed over to a voluntary organisation commissioned to support direct payments in both adults‟ and children‟s services. Other areas offer a personalised „end-to-end‟ support package from the outset commissioned from a voluntary sector provider. These organisations will also support families to access a pool of skilled assistants. Feedback from families is very positive and it is highly valued, reducing anxiety and increasing confidence.

Sutton has commissioned „SCILL‟, an external provider, to provide a holistic and comprehensive package of support. SCILL is informed as soon as a family is awarded direct payments. SCILL sets up the agreement and families can choose whether they have their own bank account or whether they would like a managed account with regular statements through SCILL. They also support the family directly in employment issues, health and safety, CRB checks and ensuring insurances are in place. They have developed a web-based recruitment agency for personal assistants. SCILL provides guidance packages for families. They monitor the take-up of direct payments on behalf of the local area and review how packages are working, exploring alternatives if necessary.

Creative thinking - There was a real sense of a desire to „push the boundaries‟ and see what could be possible when things were done differently across the most successful areas. The aim always had to be to achieve a positive outcome for the child and family, starting with what they needed and what would work best for them.

Benefits perceived by parents

Supporting normality – Direct payments and individual budgets have helped parents to regain a sense of normality as they began to feel less dependent on services and more able to take control of their own lives. Parents enjoy seeing their children being able to access activities that are widely available to their non-disabled peers and can join in activities with their siblings. The child can try different activities without the family needing to refer back to anyone.

Supporting flexibility – Families know their own needs best and there are times when circumstances change at short notice. Direct payments have enabled families to purchase support that is flexible enough to meet particular needs. They may also be used in conjunction with other models of support that are more fixed, such as overnights in a residential unit, to supplement support at times when needs are greater.

Supporting family cohesion – Being able to purchase more personalised support affords the family more opportunities to do things together. For example, paying for a personal assistant to accompany the child on a family holiday means that the main carer has a break from caring but the family remains together.

Supporting cultural appropriateness – Direct payments and individual budgets have been particularly useful to families in black and minority ethnic groups who have not been offered culturally appropriate in-house services. They have been able to utilise the flexibility of direct payments to secure their own care for their children that they are satisfied is culturally appropriate. The take-up of individual budgets however does not yet reflect the numbers of children from black and minority ethnic groups.

Individual budgets in Devon

Devon’s way of working has been developed over a number of years. This has been in full consultation with parents and carers who support the expectation of clear transparent allocations of funding within an outcomes-based framework that allows them to make choices about how they receive their support.

Parents gain direct control over the application of funding allocated to them following an assessment of need and a resource allocation process, „Fair Access to Short Breaks,‟ that brings together social care and health budgets in a pooled arrangement.

Other funding streams available to the family - including grants (such as a family fund holiday grant), universal benefits (for example childcare vouchers) and disability benefits - are also considered as part of this process, alongside normal family contributions to expenditure (for instance, activity subscriptions).

This approach enables the family to develop a service plan that meets the outcomes of the agreed care plan. This could be a combination of services that are arranged for the family by a key worker, purchased by the family from their own resources and supported by their budget or taken in full or part as a direct payment. Essentially, it is a personalised approach that provides a joined-up package of support.

Going forward with direct payments and individual budgets

Training and developing a diverse workforce - Families need to be able to access suitably qualified personnel. There is also a possibility that universal services may be affected disproportionately by reductions in funding (for example, youth services are reporting huge funding decreases and this has been a substantial growth area during Aiming High). This may lead to a potential adverse impact on their capacity to provide services to children who need additional support. Workforce development needs to be continued and strategically planned to take these issues into account.

Safeguarding of children – Disabled children are some of the most vulnerable in our society, and for many Direct Payments appear to be offering them less protection than more traditional models of service delivery. The main issues are child protection, safe service design and risk management. Clearly, there is a need to balance the requirement for increased choice and control with the inherent risks that brings, alongside the beneficial outcomes for disabled children and their families. Monitoring mechanisms that rigorously address safeguarding issues need to be in place.

Tailored support for families who have complex lives – All families should have the opportunity to achieve more control over their own lives. Many are still daunted by the concept of direct payments or individual budgets and feel that they have limited or no capacity (or energy) to manage arrangements themselves. More stories of success need to be shared and further networking of parents should be encouraged. Local areas also need to explore how to tailor support so that it does not further complicate the lives of families and thereby create an unnecessary burden for them.

Monitoring and evaluation of new schemes – This is particularly important when they are beyond the existing traditional structures and processes. Creativity is to be encouraged, but lessons from pilots need to be captured as part of the evaluation. This is particularly important in an uncertain financial climate that might lead to a more cautious approach and stifle creativity.

Shared and transparent definitions and processes – Individual budgets are a new innovation in children‟s services and the experimental nature of approaches has led to a welcome diversity. However, there is a risk of developing confusion. Published clarity around definitions will enable families and organisations to work together more effectively. It will be a challenge for local authorities to be transparent about funding in a climate where cutbacks are becoming commonplace. Equitable funding mechanisms are not going to be easy to achieve.

Effective marketing, information and clarity for families – It is important that families are clear about what is available and if services are being trialled then this should be explicit. Families also need access to timely and effective support to enable them to manage and benefit from individual budgets. Information on how this is provided and what options are available should be made clear and widely promoted. Further work also needs to be done to ensure that all those who would be eligible are being reached with information. There is under-representation from black and minority ethnic communities and this issue needs to be addressed.

Local areas have demonstrated that they have used their short breaks funding to make demonstrable progress with the personalisation agenda. The number of direct payments has increased significantly and over a third of areas are developing a programme of individual budgets as well as direct payments. As short breaks services have developed and increased, choice and capacity for personalised packages have become more widely available and demand for direct payments as an alternative may decrease. However, these mechanisms are only part of the personalisation agenda, which also includes increased control through wider participation of children and families and partnership working with other stakeholders.

There are challenges that need to be addressed in order to take this agenda forward and, clearly, further work needs to be undertaken to evaluate the impact of the drive to personalisation on the voluntary and community sector. There is a degree of confusion and ambiguity about individual budgets in many areas and how different aspects of personalisation sit together.

All areas, however, have made some progress and significantly more families have had the opportunity to take a completely different approach to having a break. Personalisation has played a key role in the development of a transformed short breaks service. The significant increase in direct payments and individual budgets, both elements of the wider sphere of the personalisation agenda, have given disabled children and their families greater choice in the way their needs may be met.

Contribution of the voluntary and community sector to the development of short breaks services

Headlines

- Collaborative approaches and more effective relationships between local authorities and voluntary and community sector organisations have been key to the transformation of commissioning practice and the development of the local authority"s role as market manager
- Commissioning of services from the voluntary and community sector has significantly increased (139%) and smaller, local providers have seen the most substantial increases
- The voluntary and community sector has played a significant role in shaping service development, delivering innovative models of service provision, supporting development of a diverse workforce and working to support parents/carers and young people to have a more influential voice in how short breaks are commissioned and delivered

Lincolnshire local authority

"We have built strong working partnerships with providers, which has added value to the quality of the services offered. Communication and information sharing has been key to building trust and a long and continued business relationship. Working together on this agenda, rather than simply issuing funding, has given more depth to the purpose of achieving aims."

Transforming approaches to commissioning

A key factor in transforming short breaks services has been a change in the way that local areas commission provision and have become more effective at managing the local market to ensure it can respond to local need. The implementation guidance stated that short breaks commissioners needed to recognise their role as market managers in seeking to use the service provider that offers the best possible combination of skills and experience to deliver services of the highest possible quality to meet individual needs at the most economical cost. The imperative then was to work in partnership to ensure that provision was commissioned effectively. Yet, in most areas, at the outset of the programme partnership approaches were under-developed in many areas with few representatives from the voluntary and community sector involved in planning and commissioning groups[22].

One of the characteristics of the areas that have seen the most positive outcomes in short breaks has been the development of successful working partnerships with providers. Over many years the voluntary and community sector has provided a range of services for the most disadvantaged children. Several organisations within the sector have worked specifically with disabled children; they have built up a wealth of skills and expertise. This has included recognising their unique perspective, experiences and the expertise they bring to the table.

Development of the market

Developing the local market was a priority for local areas and their commitment has been evident throughout the programme. This has clearly helped to promote choices and generate the local economies.

Cumbria

“Local services - this is key in a large county where many families have a 50 plus mile trip to nearest main town. Diverse ideas and approaches have led to a very positive and creative culture amongst providers.”

At the end of 2009, 44% of local areas reported that they had developed good working arrangements with the voluntary sector and another 42% stated they had basic arrangements in place with the potential to develop. This followed some concerted proactive effort from local areas where the majority of areas held provider events. These were hugely successful in facilitating a shared understanding of the vision and helping organisations to agree expected outcomes with families. In addition, they provided an opportunity to learn about what providers were already offering and how they could support the delivery of better short breaks. 98% of local areas now state that they have improved and are confident in the working arrangements with the sector.

Sutton
"We have adopted a more collaborative approach. Particular examples are the involvement of providers in service planning and development and the development of an outcomes framework tool for measuring children‟s individual outcomes."

Hammersmith and Fulham
"We have a better understanding of the services other partners provide and are better able to access their services on behalf of our clients. Therefore, clients are receiving a fuller, more considered service that is more tailored to their individual needs."

„Can do‟ solution-focused agendas were promoted to generate enthusiasm and commitment from providers at events and forums. This helped to build an environment where future providers could share their concerns and ideas with others. This resulted in providers, who may not have previously worked with disabled children feeling more empowered to do so.

Swindon
"[What has really driven this was] *the ability to solution find and/or flexibility to meet need. The positivity and shared desire to meet the wide and varying needs of children and their families gets transferred to families so that they feel that everything doesn‟t need to be such a struggle."*

Oldham

"[Providers now have] a greater understanding on their part of the needs of families and how they can best place themselves ready for the potential development of individual budgets."

Working with the voluntary and community sector as active partners

Local voluntary sector umbrella organisations were commissioned in many areas to support smaller organisations in accessing grants from other sources. This assisted with sustainability and also prepared them for the requirements of the personalisation agenda.

Northumberland

"We have been nominated for a Local Government Chronicle award for the work we have done in developing local providers. We started off with a provider event and then developed a network. This includes possibilities for sharing resources by linking providers together. For example, we linked a provider who needed transport with one who needed a venue. They are now mutually supporting each other at no cost."

Facilitating collaboration

Recognising the challenges with capacity, some local authorities have brokered opportunities for smaller organisations to collaborate on projects rather than compete. Systems for networking and working together have resulted in developing the confidence of providers. Resources are also being shared, which will assist the sustainability of smaller organisations.

Rotherham commissioned eight small local providers to deliver after school and holiday activities while the short breaks residential unit was being refurbished. These providers, including Riding for the Disabled, Rotherham United and Swinton Canal Boats have now formed a consortium „Voluntary Action Rotherham‟. They have appointed a project coordinator responsible for all eight providers and collaboratively delivered the whole out-of-school activity service across Rotherham in 2010/11.

Cheshire East
"Encouraging providers to get together and network has enabled them to refer clients across services easily providing ease of access to families."

Bournemouth
"The fact that providers are sharing staff, equipment and venues means that it‟s a more flexible, cost-effective method to provide short breaks. Also there is the potential to reduce management costs if providers share some of their management capacities as well."

Development of more accessible commissioning processes

Simpler commissioning processes have made it easier for smaller providers to receive funding that they might not have been able to access through traditional contracting processes. There has been an increasing use of small grants, significantly impacting on the ability of smaller organisations to engage.

Poole
"Organisation of short breaks opportunities has been put on a more businesslike footing. This has increased the capacity and commitment from a range of universal providers."

Outcomes-based commissioning has been developed by 83% of local areas. This has resulted in „out-of-the-box thinking" on how they could support children to enjoy and achieve.

Cambridgeshire

"For young people aged 13 plus we have an activity programme with „My Fantastic Life". The project is developing self-directed support plans for young people as they undertake activities, with these plans fitting into our personalised budget pilot."

Shropshire

"Using an outcome-based approach in establishing agreements [has changed the way we work together]; we have projects that are innovative in meeting the needs of the users and are playing to the provider"s strengths."

Support to collect data

Having good data in place to show the quantity and quality of services being delivered is fundamental to effective commissioning. A great deal of work had to be undertaken in many areas to ensure that all providers were aware of the reporting requirements, had systems in place to collect meaningful data that were able to demonstrate impact and value for money. This has worked most effectively when local authorities offered data collection support to providers.

Durham

"Providers are giving evaluation data that demonstrates the outcomes and impact of the service on children and families. Providers are also demonstrating data that supports value for money and cost-effectiveness."

Swindon

"Working with providers to gather data has helped them to develop better information capturing tools and developed their understanding of service costs and budget monitoring."

Supporting workforce development in the sector

Sharing resources and being able to access local authority and health sector training has been cost-effective and has also promoted and fostered closer relationships. 90% of local areas are providing training for voluntary sector staff and 73% of local areas are also providing training for the private/independent sector.

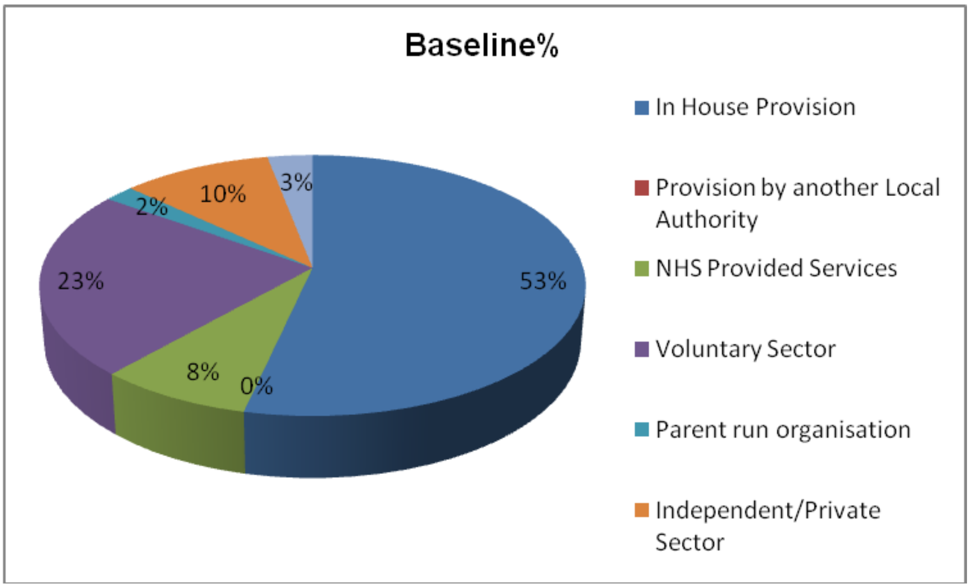
Wakefield has commissioned Barnardos to develop young people to deliver training on disability issues to staff. This includes training young people to be trainers. They subsequently deliver the training using a specially developed training pack. They also have the opportunity of becoming an accredited peer mentor.

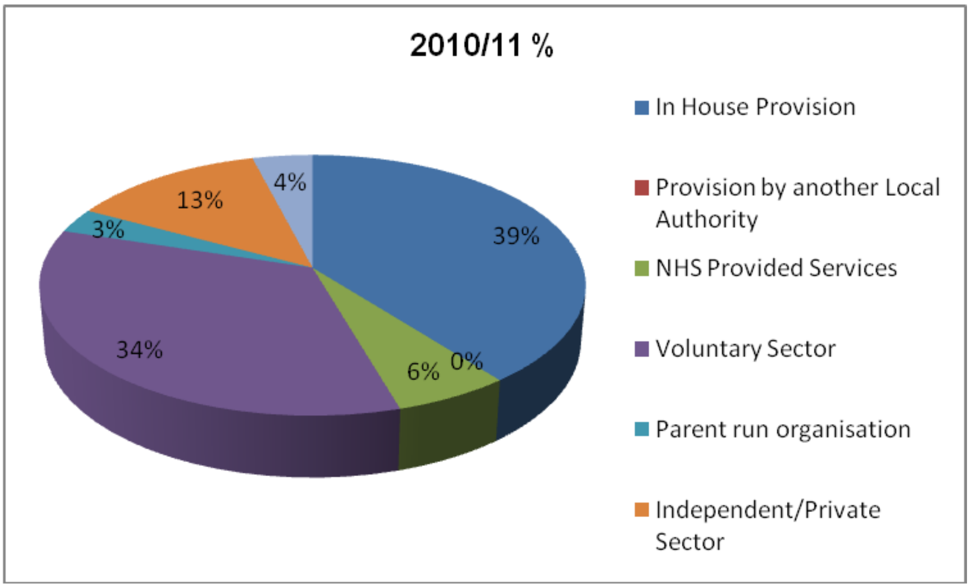
The experience of the voluntary sector, particularly with the most severely disabled children, and the expertise they have developed has enabled them to play a significant role in training and knowledge sharing.

KIDS has developed a suite of e-learning training for the short breaks workforce that has been mapped against national standards for domiciliary care, and play and youth work. There are more than 40 training modules available.

Shared Care Network runs a programme of training specially focused on short breaks provision. This includes training for family-based carers (providing overnight care) to meet Children‟s Workforce Development Council standards. These are minimum entry requirement for contract carers.

Growth in commissioning from the voluntary and community sector





There has been a significant increase in the proportion of local authority total revenue being used to commission services directly from the voluntary and community sector[23](23% of total revenue at baseline year to 34% in 2010/11). As the total revenue being spent directly on service provision at baseline was £321 million, and in 2010/11 was £520 million, this represents an approximate increase of £103 million, a 139% increase.

This growth varies greatly across the country, with some local areas commissioning the majority of services from the sector (12 areas are spending more than 60% of their revenue in the voluntary and community sector, while a further 74 areas spend more than 20% of their revenue on commissioning from the sector). Only two areas report not commissioning any services from the sector.

Additionally, according to local authority responses, the proportion of services being commissioned from parent-led organisations and independent providers, rose from a total of 12% to 17% since the baseline year.

The voluntary and community sector’s role in shaping service development

Nottingham City

“Providers are on board with the direction of travel regarding commissioning short breaks in the city. They feel involved and invested in the process and understand the government strategy. Having providers involved in setting their own output, outcome and quality targets means that they do not feel commissioners are arbitrarily imposing unachievable targets. Providers own their own targets and are involved in the rationale of setting them.”

Relationships between local authorities and the voluntary sector have certainly progressed in the majority of areas; they have moved from being providers of services to partners in shaping the way that services are developed. A wealth of innovations in service provision coming from the sector are changing the nature of short breaks, enhancing inclusion and normalising the experiences for children and families.

Novel ways of promoting services

Suffolk has developed a travel agency model. „Activities Unlimited‟ is a web-based service providing information on the range of activity options for children and young people. Suffolk has also developed a quality kitemark for activities (Triple-R), which is also publicised on the website. The cerebral palsy charity Scope acts as a broker and young people can book independently online.

The disabled children‟s charity **KIDS** has created a ‟places to go, things to do‟ online resource. This includes ideas for inclusive indoor and outdoor activities, sensory activities for children with complex needs and projects such as how to create an activity diary.

Making out-of-school activities fun-filled and action-packed

„Positive Futures‟ in **Sefton** offers a packed summer programme with over 52 activity sessions. Activities include arts, crafts and sports sessions, go-karting, sailing, climbing, scuba diving, horse riding and barge trips. The summer programme culminated in a beach party.

Bolton has commissioned a school holiday scheme from „Heart-Start‟, an organisation established by a female championship wrestler. The scheme offers the opportunity for young people to try different activities ranging from basic play therapy to freestyle wrestling, football and art delivered from an art studio based in the positive aesthetic environment of a local country park.

Getting children active and involved in sports

Barnsley Football Club was commissioned to appoint a disability sports development officer. Her role is to work with volunteers and coaches (football, rugby, cricket and multi-sports) across the areas to train and offer support to enable them to include disabled children. The relationship with the football club has resulted in four existing full-time coaches cascading the development to other universal services.

In **Staffordshire**, the Angling Regeneration team and Trentham Canoe Club have been commissioned to include disabled children in their provision of activities.

Building on what works

For many years, the sector has traditionally played a role in service delivery for children with the most severe level of needs. Organisations have been encouraged to build on what they already were doing well and expand the services most in demand by families.

Durham has commissioned additional support from the North East Autistic Society for those children who are not only autistic, but also have challenging behaviour. The menu of support that they offer comprises bespoke packages, crisis intervention, short breaks and training for families and professionals.

Emergency provision

The sector also provided responses for family emergencies.

Action for Children has been commissioned by **Telford and Wrekin** to respond to emergencies to prevent family breakdown. The charity offers a sitting service and general support to the family throughout crisis periods.

Supporting parents

The sector is playing a crucial role in building sustainability of service provision by supporting the empowerment of parents and carers. There are several examples of voluntary organisations providing training to parent and carer groups, facilitating parent consultations and evaluations of services. Voluntary groups facilitate many parent forums and some of the newly formed forums are developing as charitable groups. The sector is also providing support to parent groups to become providers of services.

Birmingham has commissioned a voluntary sector organisation to support parent groups to develop and deliver local short breaks, including holiday and Saturday schemes.

Cross sector response

The development of a more collaborative approach in some areas has shifted the emphasis from a purchaser-provider split and enabled a cross-sector response to local needs, particularly where needs are complex and interrelated. This has led to more creative ways of developing services that are already operational, reviewing how they can be enhanced and become more joined-up.

Wakefield local authority and NHS Wakefield District have jointly funded KIDS to deliver „We Sail,‟ a district-wide, one-stop early support, advice, information and liaison service. This includes key workers for children up to the age of eight years.

The Pre-School Learning Alliance runs the **Leeds** Inclusion Support Service - a single point of contact for parents of disabled children (0-19) as well as professionals. The service provides one-to-one support and advice to both parents and professionals, the administration of grants, workforce development, access to specialist equipment and a toy library for non-school settings.

Moving forward

Significant progress has been made in developing services through local authorities and voluntary organisations with a collaborative approach taken to shaping and developing the market. However, although good practice is becoming more commonplace, challenges and frustrations have been evidenced in many areas. There is certainly no room for complacency. There does need to be recognition that relationships need to be built over time to become enduring and robust. Some of the issues are serious enough to threaten even strong relationships as they have an impact on an organisation‟s ability to remain solvent.

Many areas have worked hard to simplify commissioning processes, but some are still not fit for purpose. They remain cumbersome, with complex tendering protocols and disproportionate bureaucracy, and so are still barriers to providers. This has not always been in the power of short breaks commissioners to address.

Providers have reported that timescales are often too tight to be able to respond, particularly if they had not been involved in service development and were not entirely clear of the ethos. There have been several instances where delays have resulted in the commissioned organisation not being able to deliver the expected level of service or spend the revenue allocated to them. It has sometimes been too late in the day for the authority to be able to re-allocate the unused revenue and, in some cases, this has led to underspend.

Some organisations found local areas to be inflexible with requirements for financial reporting, commenting that it was like having to „jump through hoops‟. Some providers had to progress at financial risk (particularly those with framework agreements) as they were paid a month in arrears. This is a significant barrier to smaller organisations on tight budgets.

Local areas have made substantial progress in developing their role as market managers and some innovative services have been developed in partnership with the voluntary and community sector. The sector has played a key role in providing creative service responses, supporting children and families to have a more influential voice in service development. A greater recognition that children and parent/carers have a role to play in shaping services has helped develop positive working relationships that can be built on in the future when difficult decisions about spend are being made.

Greater levels of success have been seen where commissioning processes have been reshaped (by using small grants), there is evidence of a more outcomes-based approach to commissioning and, support systems have been developed for small providers. This has all helped to give young people who have historically been disadvantaged from accessing a wide-range of breaks (those on the autistic spectrum with challenging behaviour and those with complex health needs) opportunities that they had never dreamed would be open to them and is a positive legacy of the programme.

There is anxiety about sustaining services but significant momentum has built. Systems have been put in place to support lasting change that include continued support to develop bid writing skills and mixed economy grant knowledge, as well as the development of charging policies that will assist the sector in continuing some of the achievements that they have made. Although partnerships are newly developed in many areas and therefore fragile, there is a willingness and desire to make things work that is voiced across the board. This can be built upon to take the partnerships to a more robust level. Local authorities need to be mindful of the importance of investing in their relationships with the voluntary and community sector.

Enabling a sector-led approach to support

Headlines

- A number of local authorities have demonstrated a clear commitment to the transformation of disabled children‟s services that stretches beyond their own area
- These „change champions‟ have worked with other areas to help them to progress their short breaks developments and a network of peer-led support has developed in many areas
- Change champions are continuing to take a shared responsibility for supporting the ongoing drive for improvement and are jointly developing a quality standards framework

Sector-led improvement

Achieving lasting change across disabled children‟s services is going to be tough in the current climate of social and economic challenges faced by all local authorities. It is therefore essential that the sector take a shared ownership of the need for continuous improvement as failure to achieve will have an adverse impact both on communities and on the reputation of local government as a whole. Recognising the need to develop sector-led ownership of the disabled children‟s services transformation agenda, TDC has worked closely with a number of local authorities. Initially, this was with the group of 21 pathfinders and later with a group of 18 authorities [24] that took on the role of change champions.

As a group, these change champions have developed a shared awareness of the need to drive forward improvements collaboratively to ensure that no area gets left behind. They have supported local authority colleagues successfully to improve and develop their services.

“Being able to sit alongside a colleague in another local authority and learn how they have done things was a big help to us as it gave us ideas to take back.”

“Being chosen as a champion was a real boost but we had no idea of the demands this would make upon us. It has been interesting to see how some other local authorities work.”

Pathfinders

At the launch of the short breaks programme, 21 local authorities were selected to be pathfinders. They received additional funding and were required to achieve the Full Service Offer a year in advance of other authorities and lead the way in generating learning and best practice to feed into the national network of provision.

Facilitated by TDC, a series of learning sets were held so that pathfinders could share existing and emerging approaches and innovative practice, exchange ideas and debate key issues in order to inform the wider transformation of short breaks. A set of guides on each of the issues that were disseminated to other local areas are as follows:

- Securing short breaks provision for severely disabled children with complex health needs and those with moving and handling needs
- Securing short breaks provision for severely disabled children with challenging behaviour and autistic spectrum disorders
- Eligibility and access to short breaks services
- Building the short breaks workforce
- Understanding the short breaks requirement for disabled children and their families
- Improving commissioning
- Developing the use of direct payments for short breaks

Champions

In the following year, other authorities began to demonstrate commitment to the change leadership role whilst some pathfinders needed to take a step back from the demands of the position, largely due to capacity issues and a need to refocus energy on their own programmes. TDC then launched the change champion programme with areas taking on a level of responsibility for leading change beyond their own areas.

In recognition of the additional capacity required in supporting others, some compensation was paid to these areas that all formally agreed to take on at least one of the following roles:

- Contribute to the development of short breaks guidance products
- Present identified good practice to at least two regional events
- Provide mentoring or individual problem-solving support to a least one local area
- Facilitate learning clusters
- Undertake research projects proposed by TDC
- Develop case studies to illustrate good practice

Although there was no further resource for additional capacity in the third year of the programme, commitment to champion change was still in evidence and the group wanted to continue in the role, clearly recognising the importance of the sector itself needing to take on the responsibility for driving forward the agenda for change.

Sunderland has led on establishing a Regional Disabled Children‟s Network in the North East involving all strategic leads.

TDC continued to facilitate the programme and other authorities were invited to participate. The criteria was that areas needed to be making good progress themselves, be willing to share learning with others and take on a wider change leadership role in some way. Regular meetings were held to encourage and promote networking among champions, ensure that they were well informed about overall programme progress, developments and challenges, and provide opportunities for training.

The role of change champion has been well received by those adopting the position and those benefiting from the support. They have been instrumental in feeding back from the field current issues and challenges, as well as success stories. This has influenced TDC"s response to support and the development of guidance tools. Cluster groups across the country have enabled all local authorities to network, share practice and challenges. These have been, and are still being, facilitated in some areas by change champions. Change champions have also played a key role in developing learning sets that have proved to be an effective model to enable local authority colleagues to work on specific issues and test ideas in a closed, supportive environment.

Hampshire, working in conjunction with **Southampton** and **West Sussex**, has led the development of a quality assurance framework. There are two elements to the framework that have been significantly progressed; one for parent assessed services and one for services that have been assessed by children themselves.

PAT Mark and CAT Mark

The PAT Mark is a stamp of approval for disabled young people‟s services and is awarded by parents who have been trained as PAT Mark assessors. They assess services, organisations and projects against set conditions. Being awarded a PAT Mark shows a commitment to providing a good quality service that successfully meets the needs of all disabled young people and their families. The parents‟ forums have been instrumental in supporting the development of the PAT Mark and there are clearly opportunities for parent forums to be commissioned to develop it in their area. This would help to sustain parent forums and provide additional opportunities for increasing parental involvement. The CAT Mark is the equivalent quality mark given by young disabled people who have been trained as quality assessors.

Summary

The authorities that have acted as change champions have demonstrated clear commitment to the agenda of transformation and service improvement for disabled children and their families. This goes beyond their own areas and is driven by a shared ownership of the issues that have an impact on families and a shared vision of how life could be made better. They have shown a willingness to offer practical support to other areas, facilitate cluster learning events and share learning from their own areas, as well as acting as „critical friend". These approaches have been well evaluated by other areas.

Whilst it is important that learning is disseminated and local areas support each other, there is a cost to this. Local areas need both the capacity and expertise but also the resource to coordinate and facilitate networking with other peers in a similar role.

Factors contributing to successful transformation

Headlines

- Seven factors have emerged that are central for successful transformation
- Three of the these are identified as the essential factors common to a number of areas, that have led them to „stand out from the crowd" and to help explain the particular success demonstrated – passionate commitment, collaboration, innovation
- The remaining four factors all emerge as strategies that have enabled improvement and supported the journey to successful transformation: – leading from the front; strengthening structures; focus on fairness; knowing the numbers

Introduction

From the start of the programme, it was clear that local areas were delivering levels of services that differed greatly across the country. All areas started the journey of transformation from a different place and could therefore be expected to progress at different rates.

There were a few areas that immediately stood out from the crowd as they were already demonstrating commitment to developing provision and to working with parents. AHDC energised these areas and they grasped the opportunities for progress with both hands (some had campaigned themselves for the resources), but it is likely that they would have been determined to improve their services anyway, albeit with very limited resources and changes being far more modest. The expectations of these particular areas were naturally high and they were considered to be front-runners.

However, by the end of the first year, it was clear that other areas were progressing rapidly and delivering service level improvements that were far higher than had been expected. In contrast, there were areas that were clearly experiencing challenges and frustrations and others that were making progress but at a much slower rate. In short, there were many surprises and nothing could be taken for granted.

TDC identified high achieving areas using a value for money framework mechanism that took account of the area‟s reach, cost per child, proportion of direct payments, level of service per child and the unit cost of each model. This hard data was triangulated with the qualitative information offered by local areas as evidence of their progress towards the Full Service Offer and also with information collected from parent carer forums on the parents‟ perspective.

In order to support areas to continue progressing and to secure lasting change in a climate that is financially challenging, it is essential that there is as much clarity as possible about what drives forward transformation and supports sustainability. The key question to address is, *„What are the factors most likely to enable successful change and bring about the most positive outcomes?‟*

TDC has worked alongside local areas in learning sets, cluster groups, champion networks, as well as one-to-one contacts and has captured the evidence of progress as well as the lessons learned about how that progress has been facilitated. Some common themes have emerged, particularly over the last year as local areas themselves took more time to reflect on what have been the factors that have enabled them to achieve the most positive outcomes and significantly increase the volume and range of short breaks that they provided, improving quality so that parents and children were satisfied with provision.

To further validate the themes that emerged over time, TDC also facilitated a number of focus groups and semi-structured interviews [25].

Factor 1 – passionate commitment

Few pieces of work or service improvement programmes have generated as much passion as this one. Passionate commitment has been a pervading theme since the policy initiative was announced and has been a feature throughout. It has shown itself in the way local authority officers, parents and professionals have been so willing to give additional time to the work that needed to be done, over and above what would ordinarily be expected of them and in the way they talk about the work they have been involved in. People use emotive language that is clearly more than rhetoric; it has arisen from the changes they have seen and been a part of. There has been a hunger to learn from other areas, to test out what works best and an overt willingness to share ideas that has fuelled energy for change that is not often seen.

Quotes from local authority officers:

> *"I feel humbled to have been part of this programme. It is the thing I am most proud of in my whole career."*

> *"It has changed everything about the way we work. There is no going back now… this is how we do things round here."*

> *"I can't adequately describe just how amazing it has been to be part of this. It does something deep in my heart to see what we've achieved together."*

Factor 2 - collaboration

Within this theme there are two strands – partnership with parents and working relationships with other sectors.

Partnership with parents - This report has already made much of the importance of working with parents and ensuring that they are at the heart of commissioning processes and service planning. This is such an essential factor that it cannot be over-emphasised. Across all the high achieving areas, however, parent participation was acknowledged as an essential element to achieving better outcomes. In the majority of these areas, parents have moved into a relationship of being a co-producer: they now understand the pressures on services and are working with professionals to generate solutions.

Repeatedly the issue of parents „not asking for much‟ has arisen. Few parents ask for more than they really need: they appreciate that resources are finite and they want to see other parents benefit too. They want the best for their children and their experience and knowledge are assets that are essential to building better services. Areas that are doing well know this and have maximised the opportunities to develop strong partnerships in which they will continue to invest.

Another lesson from working with parents is that of the need for information to be clear and concise. Parents want to know what is available and how they can access it. They also want to know how they can get advice and support when it is needed and they want that to be timely. Local areas believe that it is too easy to overcomplicate systems, adding bureaucratic layers that slow things down. Simplifying processes and making information more accessible has freed up more time and improved satisfaction more than they could have imagined.

Working relationships with other sectors - Clearly, authorities need to invest energy to build relationships with parents as the carers of the children using services, but the voluntary and health sectors have an equally crucial role to play in planning and delivering better services.

Where there have been constructive relationships and evidence of partnership in action, there has been real progress made with some innovative and collaborative solutions generated.

> *"Every child who needed postural care management received a quality service through investment in equipment and embedded training and support to all health and appropriate social care staff."*

A number of areas talked of not just themselves needing to develop a relationship with parents, the voluntary sector and health sector but of the necessity for all to work together as a collaborative venture.

> *"It"s been like a family really, all working to improve things for disabled children and their families. I would not have missed this for the world. It has been such a privilege."*

More progress was made in areas where there was a history of collaborative working between key agencies. Many successful areas had pooled funding arrangements, but these were not a feature of all high achieving areas. What appeared to matter most was clarity about the level of resource being contributed, whoever was actually managing the budget.

Factor 3 – innovation

It seems to be that the more passionate the commitment and the better the level of collaboration, the greater degree of innovation there was. There is something about working well together that creates a climate of trust. This fosters creativity as people are more willing to take risks in the way they generate solutions. Innovation is about looking at things and seeing how they might work differently. It is also about starting with outcomes - looking at the benefits for children and their families and working back from that. Sometimes, it is simply about trying something out and seeing how it works in practice with no prejudice. Innovation appears to have led to some great examples of cost-effectiveness. It might have seemed an odd idea to take 20 families with their disabled children to a funfair. However, if most of those parents felt supported, listened to, had a break from caring and saw their children having fun with others, then a great deal has been achieved for relatively little outlay.

> *“The important thing has been looking at what a short break actually means to families – by understanding that and starting with it you get to a different place and do it differently. It is about being brave enough to try.”*

Factor 4 – leading from the front

It was very important that there was a dedicated officer leading the programme. Across the country, there were different models of leadership and management and no one model has emerged as being vital. However, the common factor was that there was a named person managing the change programme and, if that person was not in a senior position in the authority, that there was also a named strategic lead who was in a decision-making/budget-holding position who could have influence at board level.

> *“I was project manager and reported directly to an assistant director. I think it worked best as I have been around a long time in senior jobs and people know me.”*
>
> *I had a project manager reporting to me and could leave her to do all planning and operationalising of everything that was decided. I could still do the „day job‟ but knew everything was on task.”*

This was a complex programme of change requiring detailed planning and demanding communications at many levels. Several authorities did not have a dedicated project manager and clearly found it a challenge to manage all the activities required.

> *“It has been all I have done for last two years. I‟ve eaten and slept this – I don‟t know how anyone can do it and run a department.”*

Factor 5 - strengthening the structures

Good governance was an important characteristic. There had to be clarity about reporting structures and where responsibilities lay to avoid causing delays, especially if the short breaks lead officer was not in a senior position. Structures that enabled effective communication and timely authorisation of out-of-the-ordinary decisions were essential.

There also had to be structures in place to ensure that parents and other partners were feeding directly into the overall decision-making processes.

> *"The Board met every month and we knew when so could make sure reports were ready. We were a standing agenda item."*

> *"Our planning group meeting was always two days before Board so we could feed in – it worked well – we had to have everything ready in time. Also, PCT being on the group helped and it was jointly chaired by her and our Assistant Director – so they always knew what was going on."*

Factor 6 – focusing on fairness

A common feature of the starting point for change across successful areas was one of beginning with the principle of fairness or equity for all children. Some areas clearly believed that the fact that disabled children were not able to access play and leisure facilities was a key factor in exacerbating the need for short breaks.

> *"If they‟re in for days on end with their children, not seeing anyone else and never getting a break from that – of course, it‟s going to be awful."*

"We started from „What do all kids need? What do parents want for their kids? How can we help families stay together?" It"s subtly different from starting with „How do we do more short breaks?" as you"re starting before things get so bad that a night away is all that"s going to help."

The objective was to find a way to enable greater choice of activities that were open to all and that parents were confident could support the need of their children. This would not only free up social work time, a limited resource, but also enable children to start using a service more quickly. This principle has led to the development of local offers and open access activities (many supported) that form the first tier of short breaks services in many successful areas.

Factor 7 - knowing the numbers

The areas that have had most success have embraced the need to be well-informed so that they can make effective commissioning decisions and invest resources into detailed population strategic needs assessments, mostly in partnership with the health sector. They also drew on the expertise of data and finance officers to support them, some of who became part of the programme team.

"J was part of the AHDC team and that was brilliant. She has really helped us make sense of our data – so it tells us where we"re doing okay and what more we need to do – and helped all providers to collect information we need."

"K saved my sanity! He knows nothing about children but everything about finance and we now know the costs of all our services and where we are spending most and saving. He has kept the spending on track – essential."

Moving forward

Passionate commitment clearly cannot be manufactured and not every local authority will have officers who feel so strongly about the needs of disabled children. However, all authorities have parents and structures are in place now for them to be in a position to partner with managers and professionals and become part of the driving force for change. It seems to be that the effort that needs to be invested into developing relationships with parents, and with other sector colleagues, generates of itself, something of the passion that is needed. Listening is fundamental to relationship building. Hearing the stories from parents and families about the way that a child‟s disability can have such a disadvantaging impact on the child‟s and indeed the whole family‟s life, can go a long way to nurturing passionate commitment.

It is this key factor that appears to bond collaboration and innovation together and, clearly, they are inextricably linked. The other factors are all ways of approaching projects and can be developed in any area that is intent on bringing about lasting change. Adopting these factors as strategies and making an explicit commitment to resourcing and nurturing relationships with parents and other partners, set the building blocks in place for the fostering of a climate where innovation can flourish.

Outcomes of transformed short breaks

Headlines

- Disabled children and young people are experiencing increased choices, wider social networks and are growing in confidence and independence
- Parents are experiencing more choice and control of family life, developing supportive peer relationships and have raised their expectations and aspirations of what their children may achieve
- Families are experiencing less stress and becoming more resilient and better able to carry on caring
- Local authorities are seeing 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

Durham

"Without a doubt our short breaks programme has delivered not what ***we*** *thought people needed, but what people actually wanted. As a result, we have delivered a hugely successful programme at a low cost per unit price. This has enabled us to support more families and work on our strategy of reducing high cost places. In terms of that, if we reduce just one place per year a saving of £220,000 will be made. [We have calculated that we will see] a real reduction in cost that could equate to more than £500,000. If we can develop this trend we are confident, and research supports this, that we can reduce our costs substantially. However, initial investment [in developing short breaks] is of paramount importance. This cost benefit has been achieved by asking parents what they need and providing it. They are the experts."*

The aim of the short breaks development programme was to ensure that all parents of disabled children, where there was a need, were able to access a choice of regular short breaks from the responsibility of caring. Given the substantial increases and the improvements in access, there is evidence that this aim is being met. Thousands more families are benefitting from a short break now. However, the impact reaches beyond than this and many additional positive outcomes are being seen for children, for parents and also for commissioners of services.

Outcomes for children and young people

Increased choice and decision making

There is evidence that disabled young people are being supported to take more control of their lives, take risks appropriate to their age and development and make choices about how to spend their time.

Wakefield

„Where this Weekend?" project - Support workers are trained to help young people decide where they want to have their weekend overnight breaks. The youngsters are then involved in making all the arrangements for the weekend stay – locations have included camping trips, youth hostels and each others" homes.

Increased social networks

Disabled children often feel isolated and not part of their community activities but through the programme children report that they have developed friendships and widened their social network.

> *"A loves the play scheme - it gives him an opportunity to meet friends out of school."*

"C has so many new friends – spends ages on Facebook now keeping up with them all!"

Increased independence and confidence

Activities have been designed that not only enable children to have fun, but stretch them and help them to grow in confidence. Some of these have enabled young people to travel further afield and learn skills that they might never have dreamed of.

Leicester City, with their "Big Mouth" Disabled Children and young peoples forum organised Rising Star Awards with children singing, reciting their own poetry, dancing and performing sketches, and demonstrating their own skills at particular activites, including martial arts. Several of the children had little confidence, few friends, and some were unable to make eye contact at the start of the AHDC programme but by the end were able to stand on the stage in front of a large audience and perform.

Surrey has developed „Disability Challenger" play and youth schemes across the county, offering a diverse range of activities for a large number of disabled children, many of whom have severe and complex needs. The scheme is highly valued by parents.

Disabled children have been able to participate in sporting activities that were previously inaccessible, due to investment in adaptations and staff training.

The development of the **Croydon** Sport Development Team has increased opportunities for all disabled children to take part in a diverse range of sports activities. These range from water sports in Docklands, wheelchair users taking part in the London Marathon, swimming and trampolining. New sports equipment includes basketball wheelchairs. This has proved to be highly successful and enables children to grow in confidence from the successes they achieve.

Bournemouth will make the newly developed seafront at Boscombe Pier, with all its new restaurants and beach activities (including artificial surf reef) and park with play facilities, easily accessible for disabled children, young people and their families. The whole project will be completed with the procurement of up to five special wheelchairs that will enable children and young people to make best possible use of the beach.

Outcomes for parents

Increased choice and control

Families now have more choice of services as the range of provision has grown.

Increased networking and peer support

Relationships have developed through a combination of the ongoing participation and planning work and the delivery of whole family support events. This increased opportunities to meet other parents and has facilitated peer support.

Knowsley
"Families have developed support networks that did not exist before. They have formed friendships that create an informal mutual support network, which promotes their own sense of wellbeing and ability to be less reliant upon services provided to them. It has opened up other areas of mainstream provision to children that previously were closed to them and broken down barriers."

Increased resilience

Short breaks appear to have made a huge contribution to the prevention of family crises by decreasing the stress levels experienced by parent carers. Caring can be a stressful business and it is essential that families feel supported. The knowledge that a regular, planned break can be taken is clearly beneficial.

"*The stress of caring has been reduced because of regular breaks and the increased information provided has given me greater reassurance."*

Brighton and Hove parent

There are many examples cited from parents who say their relationship has improved and they were able to lead more ordinary lives, with examples of families going out together as a family for the first time.

"Short breaks have saved my marriage."
A couple who had not been out as a couple for 14 years

Haringey
"Families show greater resilience and have benefited from meeting and supporting each other."

Increased expectations and aspirations

Parents‟ expectations have been raised in terms of the type of short breaks available, as have expectations of what their child could achieve. Parents talk about having a greater level of confidence in their child‟s ability, having a sense of being able to „let go‟ and therefore less likely to be over-protective. Trust in wider universal services has grown as providers demonstrated more proficiency in supporting young people with complex needs.

Outcomes for services

Decreased social care interventions

Short breaks have become part of the family support/early intervention strategies in many areas and the benefits of the strategy are being seen in the decreased need for social care interventions. Fewer emergency placements are being reported – in some authorities by as much as 50%. Many areas are also seeing a significant reduction in calls to the duty social work team. Having a good level of provision that meets the needs of the families needing support prevents crises arising later on.

Halton

"We now have lower numbers of children receiving social work but are reaching more children."

Kingston upon Hull

"The creation of more flexible services has changed how staff respond to urgent emergency service requests. An example of this is that when various requests to accommodate children have been made this has been avoided by the use of the newly created services."

Decreased numbers of looked after disabled children

Short breaks prevent many disabled children entering the looked after children‟s (LAC) system. TDC research [26] with 17 areas showed that they were successfully using short breaks as a means of preventing children entering the LAC system and from requiring emergency, high cost placements, particularly when a high level of good quality short breaks provision was offered in school holiday times. The cost-savings for the 22 children in the study across the 17 areas were reported to be almost £2 million [27]

Walsall
"We‟ve received no requests for children to become permanently looked after since 2009 - parents report that the support they get has enabled them to remain as full time permanent carer of their child."

Many local areas gave individual cases as examples of how short breaks had prevented children becoming looked after.

"A mother rang to say she could no longer manage her son at home due to his challenging behaviour. We were able to provide flexible short break support, which has seen him remain at home and allowed mum to feel still in control of managing her son‟s care."

Decrease in costly placements

Short breaks are likely to reduce the need for costly out of borough placements. During the programmes, children living in „out of area‟ placements have decreased considerably (2,779 to 2,552 – 8% decrease) and this will have a huge impact on budgets. Local areas in the study, for example, reported that they were spending almost £3 million for 22 children in out of area placements per year. Supporting them with wrap-around short breaks packages (at a cost of around £380,000) will enable some of these children to return to live at home and thus save significant sums of money.

Moving forward

The Short Breaks Regulations (Breaks for Carers of Disabled Children Regulations 2010) became statute in April 2011 and prescribes how authorities should carry out their duty to provide a service to carers of disabled children. By September 2011, all authorities will be required to publish a statement of the provision available and their criteria for accessing services. The benefits of provision of short breaks outlined in the report should offer authorities additional impetus for continuing to invest in short breaks development.

Section 3: Sustaining lasting change

Next Steps and Recommendations for Securing Lasting Change in Parent Carer Participation and Development of Short Breaks

Recommendations

- Continue with data collection and analysis to underpin effective commissioning and evaluation - demonstrating the outcomes and impact of parent carer participation and service development is essential

- Continued support to strengthen parent carer participation – many forums are in the early stages of development - structures are fragile and still need to grow in strength and influence

- Consider development of local offers and open access frameworks - improving access and widening the range of breaks available has been a cost-effective strategy

- Review the reach of short break services – access has increased but there are more children who would benefit from short breaks that are not yet receiving them

- Invest time and energy in the development of partnerships across sectors, particularly with the health sector, voluntary and community sector organisations and universal children‟s services - effective working relationships are fundamental to achieving better outcomes

- Target children with the severest level of need – parent carers of children with the most complex of needs may not always seek out early support

- Develop personalisation approaches and make more widely available to all families - personalised strategies have enabled parents and children to have increase choices and more control over their own lives
- Responsibility for service improvement should be owned by the sector
- Investment in service development and embedding transformation needs to continue at national and local level
- Disseminate learning and factors of success

Drawing on the lessons learned about what has enabled effective developments and has led to improved outcomes, the following recommendations are made so that local areas can give consideration to the next steps in their planning for the strengthening of parent carer participation and development of short breaks services.

Continued data collection and analysis to demonstrate outcomes and impact

There is an abundance of evidence to show that robust data (both quantitative and qualitative) leads to a more informed approach to commissioning and enables improved decision making around service planning. Assessment and identification of population needs cannot be a one-off event; information needs to be continually updated and undertaken in partnership with the health sector. More so in these times of financial challenge, the need to demonstrate outcomes for children and families alongside cost and effectiveness of interventions is important. Short breaks have been shown to be an effective model of providing early intervention that can save money in the longer term and enables families to become more resilient. Many areas have indicated their intention to continue collecting and using data and it needs to be a central component for all areas.

Strengthening parent carer participation

The strengthening and development of parent carer participation and parent carer forums is one of the strongest legacies of the last three years. Parents have been empowered and in many areas are true partners in decision-making about services for their children, young people and their families.

For some, it has been a challenging journey but there is no going back from the position that forums and local areas now find themselves. Parent carer participation has begun to be ingrained in service planning, delivery and evaluation. The positive outcomes for children, young people, their parents and carers and for service providers, as evidenced in this report, show the benefits of this approach.
The development of the regional and national network further embeds the tenets of parent carer participation, and reflects the work of local parent carer forums at regional and national level. For parent carers, knowing that they have a meaningful voice not only in their local forums, but also in national developments is extremely important. The plan to ensure locally elected membership will further strengthen its representative influence.

Ensuring there are continued development opportunities for new parent carers, and succession planning, is key for forums. Support in the potentially challenging years ahead, and some of the complexities that may arise in light of the economic climate, also mean the forums are likely to require some ongoing support. The continued investment from government through grants to local forums, and the intention to commission a delivery partner to support parent carer forums is widely welcomed and goes a long way to acknowledging the importance of participation.

At a local level, authorities need to strengthen their relationships with parent carers and make governance structures more robust so that participation becomes further embedded. What cannot be denied is the value that is added to service planning, delivery and evaluation by the participation of parent carers.

Continue to improve access to short breaks services and consider use of local offers

In April 2011, new legislation, in the form of the Short Breaks Duty came into place and, as a result, all authorities are required to publish a short breaks statement, detailing the provision available and their entitlement frameworks by September 2011. Many authorities are in a position to be able to fulfil these legal requirements, yet others will need to undertake further work to meet them.

Many areas are already offering an entitlement model of provision and finding that it frees up more social work time, cuts down bureaucracy and enables a speedier intervention with parents being able to access many services without becoming „part of the system‟. It is recommended that other areas give serious consideration to this model as the benefits are wide-reaching with many reported positive outcomes for families.

Review reach of short breaks services

Undoubtedly, access has improved. However, there are some authorities that have made more modest improvements and it is recommended that they continue to review the reach in their own locality and work to increase this, particularly in areas where it is below 1%.

Invest in partnership working across sectors

There is a greater range of choice in types of provision available, as well as a marked increase in volume of short breaks. This has largely been brought about through effectively working with partners – in the health sector, voluntary and community sector and across wider children‟s services. Time and energy to develop these relationships is key to ensuring sustainability. There are challenges to this as all services are facing financial challenges and it is going to take imagination and commitment to ensure sustainability. Workforce development remains an important factor if universal services are to be able to share the responsibility for service provision and enable more disabled children to access opportunities available to their peers. Working together is fundamental to taking this forward.

Targeting children with the greatest level of need

There has been significant progress made but many areas have faced challenges in developing services for children with the most complex needs. It is recommended that areas adopt a targeting strategy to endeavour to reach this group with information and promote services. These are families that often cope until crisis point, as they may not have the same amount of time or energy to seek out early interventions themselves. Short breaks make such a difference to the lives of families so professionals do need to be proactive in promoting services. Further investment needs to be made in staff training and in building relationships across sectors, particularly with health professionals so that targeting approaches are jointly owned and delivered.

Develop and widen availability of personalisation approaches

There has been demonstrable progress with the personalisation agenda. As short breaks services have developed and increased, choice and capacity for personalised packages have become more widely available and demand for direct payments as an alternative may decrease. However, these mechanisms are only part of the personalisation agenda, which also includes increased control through wider participation of children and families and partnership working with other stakeholders. There remains a degree of confusion and ambiguity about individual budgets, in particular, and how the different aspects of personalisation sit together. The concern is that personalisation will be disproportionately affected by budget cuts; however there is no evidence at this stage that this is happening. Direct payments and individual budgets may not be what all parents want but it is important that the choice is available to all.

Responsibility for service improvement should be owned by the sector

The last three years have seen significant investment and a centrally driven transformation programme. The Department for Education intends to commission a delivery partner for the next two years to continue supporting local areas to embed change and ensure continued improved outcomes for children and parents. However, the drive for improvement needs to be gradually decentralised and the sector itself should take on the joint responsibility for setting standards for service delivery. Cluster groups and regional networks were highly valued by local authorities during the course of the programme and it is recommended that the sector takes over the responsibility for ensuring these continue as a mechanism for sharing good practice, generating solutions to shared challenges and providing peer support.

Commitment and continued investment at national and local level

The Government has put disabled children and their families at the centre of its agenda for change in children‟s services with over £800 million being made available to local authority areas through the Early Intervention Grant. TDC asked all local areas for information on their 2011-2012 budgets. This should mean that all authorities are able, at the very least, to maintain the level of expenditure on short breaks provision as the total amount available per year is greater than the amount available previously.

At the time of going to press, only 42 areas were in a position to be able to confirm their budget allocation and the emerging picture is a concerning one. Of the 42 areas that responded, only seven are increasing their spend on short breaks. 35 areas are reporting a decrease; 22 of these reporting a decrease of more than 40% from last year and the greatest decrease is 76%. Several authorities that were unable to confirm their budgets have reported that they are receiving nothing from the Early Intervention Grant.

At the time of the progress reviews, authorities reported that budget restrictions were their greatest challenge. It was to be expected, given the challenging economic climate, that services would experience reductions in budgets, however short breaks for disabled services have been subject to under-investment for many years and transformation is at a very early stage. To ensure that changes are lasting and embedded, investment needs to continue to grow for at least a further four years. Positive outcomes, for children and families, and for services that are seeing more value for money, are beginning to be evidenced and many other longer-term outcomes will be seen over time, if investment continues.

Disseminate learning about factors of success

Of course, money is not the only issue, there has to be a continued commitment to ensure that disabled children are kept as a shared priority within children‟s services. It is recommended that lead officers disseminate the learning from this report, present the key findings to other colleagues and to members, and share with parents.

Summary

There has been a remarkable transformation made to services for disabled children and their families over the course of the past three years. More parents are involved in local service planning and they have a greater say in how decisions are made. They are developing a collective voice in shaping policies at a national level and this is enabling them to have a greater level of control over their own and their children‟s lives. Short breaks services have increased significantly, with a greater range available, more choice and easier access. Disabled children and young people are having more of a say in how services are commissioned and the programme has been a catalyst for increasing their participation. Disabled children are enjoying more opportunities to engage in ordinary activities and are increasing their social networks, as well as increasing in confidence and skills. Positive outcomes are being seen for services too, and they include fewer children needing emergency social care interventions, less reliance on costly out-of-area placements and fewer disabled children becoming looked after.

This report has given a wealth of information about the journey of transformation and a vast range of examples of where things are working well. This is only the beginning. In many ways, achieving the changes, notwithstanding the challenges involved to do this, has been the easier task. The toughest one is to embed change and make it last. It seems fitting that a parent carer of a disabled child should have the last word in this report:

"Now, we have services that we actually want, they cost less and she is so much happier – and she is learning more and growing in confidence. It would be madness to stop this. Whose purposes will that serve? No, there is no going back."

Footnotes

1. The Breaks for Carers of Disabled Children Regulations 2010.

2. Formerly and at the time of commissioning, was the Department for Children, Schools and Families (DCSF).

3. Action learning set – a process led by a facilitator, where individuals come together in supportive groups to work on real challenges, using their combined knowledge and skilled questioning, and re-interpret old and familiar concepts to generate fresh ideas and solutions. It is a tried and tested powerful learning tool enabling leaders to learn from each other.

4. *„Aiming High for Disabled Children: Short Breaks Implementation Guidance‟* 2007: Department for Children, Schools and Families.

5. National Development Team for Inclusion (NDTi) - Short Breaks Pathfinder Evaluation: Grieg, Clayson, Goodey and Marsland: 2011).

6. *Positively Parents: Caring for a Severely Disabled Child*, Beresford, B, SPRU, York.

7. Report of the Three BME pilot projects - TDC

8. See Footnote 7.

9. Reference as Footnote 6.

10. Four of these 16 areas report a reach of over 5% in end of year data, but these statistics were not validated by TDC.

11. The two groups were determined at the outset of the programme after amalgamation of the range of needs identified as more likely to prevent a child being able to access a full range of services or being seen to be „too complex‟ for services to be able to offer breaks to. These included: children with challenging behaviour, those with autistic spectrum disorders and severe learning disabilities, older children with moving and handling needs, those who needed medical or technological support or who needed specialist equipment to communicate.

12. Group A – Children on the autistic spectrum who also have additional needs such as behaviour that challenges and children whose challenging behaviour is associated with severe learning difficulties (not all children with autism will require short breaks).
Group B – Children and young people with complex health needs - including those with a disability and life-limiting conditions and/or those who require palliative care and/or those with associated impairments such as cognitive or sensory impairments and/or have moving/handling needs or require special equipment and adaptations.

13. 16 areas that had made exceptional progress in developing services for children in priority groups took part in a TDC study to identify and confirm the factors of success. These areas were Lambeth, Bolton, Warwickshire, Essex, Plymouth, North Lincolnshire, Newham, Suffolk, Kent, Harrow, Medway, Walsall, Dudley, Durham, Birmingham and Bromley.

14. Two of the 152 local authorities were not providing any direct payments in 2007.

15. There is an issue around calculating the average amount paid to families for direct payments as authorities were asked to report on revenue being used for either direct payments or individual budgets. The „average payment‟ therefore needs to be viewed with regard to this issue.

16. Now the Department for Education.

17. Evaluation study of pilot programme to test implementation of individual budgets in disabled children‟s services.

18. „In Control‟ is a national charity that operates an extensive community network working for change and to provide people with the knowledge, power and tools to control their support.

19. One authority has delivered a significant number by itself: 1,011 at baseline, increasing to 1,400 by the end of 2010/11.

20. Local authorities that have shown demonstrable success in delivering direct payments worked with TDC to determine factors that contribute to success and continuing challenges. The local authorities involved were Sutton, Nottinghamshire, Darlington, Wirral, Warrington and Hull.

21. Local authorities that contributed to the work around on individual budgets were: Devon, Halton, Islington, Middlesbrough, Newham, North Tyneside, Suffolk and Wakefield.

22. According to independent evaluation cited in Implementation Guidance.

23. Facilitated Self-Assessed Progress Reviews carried out by Local Authorities in December 2010. Authorities were asked to indicate how their total short breaks revenue was proportioned in baseline year and again in the financial year of 2010/11

24. Bolton, Buckinghamshire, Cambridgeshire, Devon, East Sussex, Gateshead, Gloucestershire, Enfield, Hampshire, Kingston upon Hull - City of, Norfolk , Oxfordshire, Suffolk, Sunderland, Sutton, Tower Hamlets, Wakefield, Wiltshire were all part of the change champion programme in at least one year.

25. Ealing, Essex, Durham ,Gateshead, Hartlepool, Middlesbrough, Reading, Slough, Warwickshire, Walsall, Telford , Liverpool, Oldham, Gloucestershire, Bristol, West Sussex, Enfield, City of Leicester, Redcar and Cleveland, Kent, Plymouth – all these areas identified as having made excellent progress in at least 2 spheres of the programme, using triangulated quantitative and qualitative evidence.

26. “Impact of Short Breaks on Prevention of Disabled Children entering the Looked After Children system” report by TDC v2.0 January 2011.

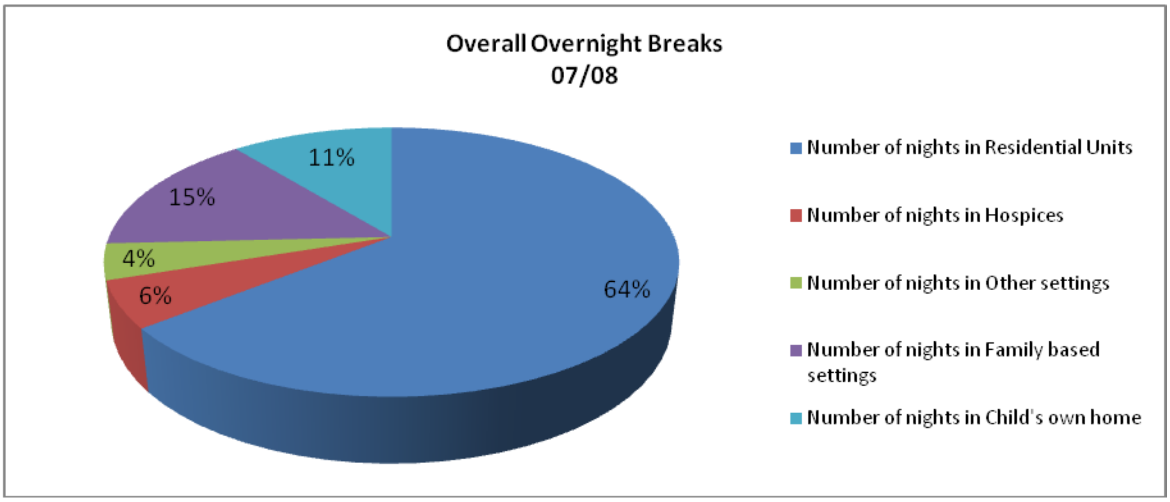
27. Cost of placements for the 22 children was calculated by the authorities themselves as £2,226,162. Reported cost of short breaks for the same children was £374,605 – thus the potential cost savings were estimated to be £1,851,557.

Appendices

Appendix I – tables and charts showing increases across all models of service provision and the change in proportionate shape

Table showing increases in overnight stays from 2007/08-10/11

Overnight Stays (Nights)	Actual 07/08	Actual 10/11	% Increase
Number of nights in Residential Units	377,391	451,070	20%
Number of nights in Hospices	32,971	46,797	42%
Number of nights in Other settings	25,397	57,151	125%
Number of nights in Family based settings	87,494	112,096	28%
Number of nights in Child's own home	63,842	113,713	78%
Total Number Of Overnight Stays	**587,095**	**780,827**	**33%**



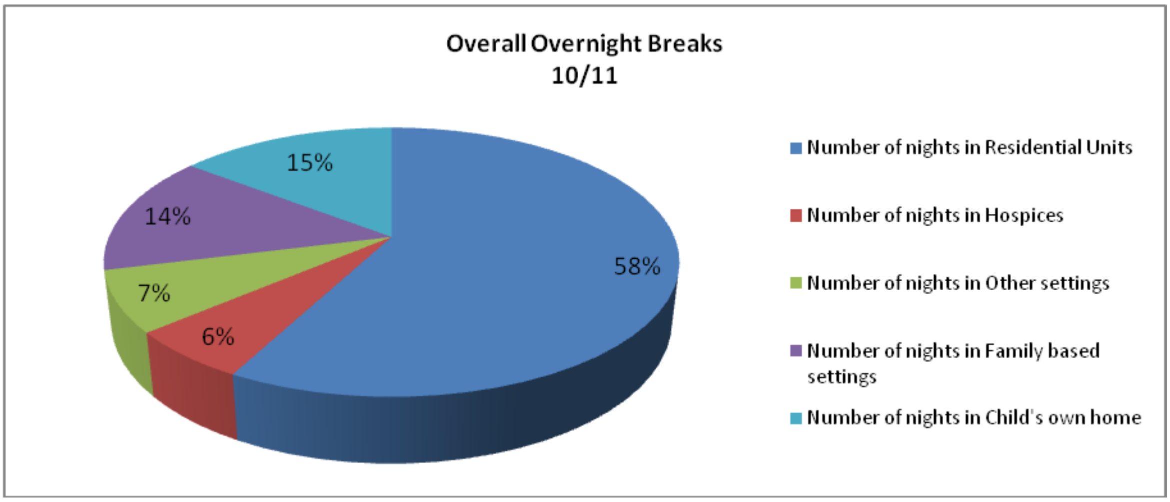
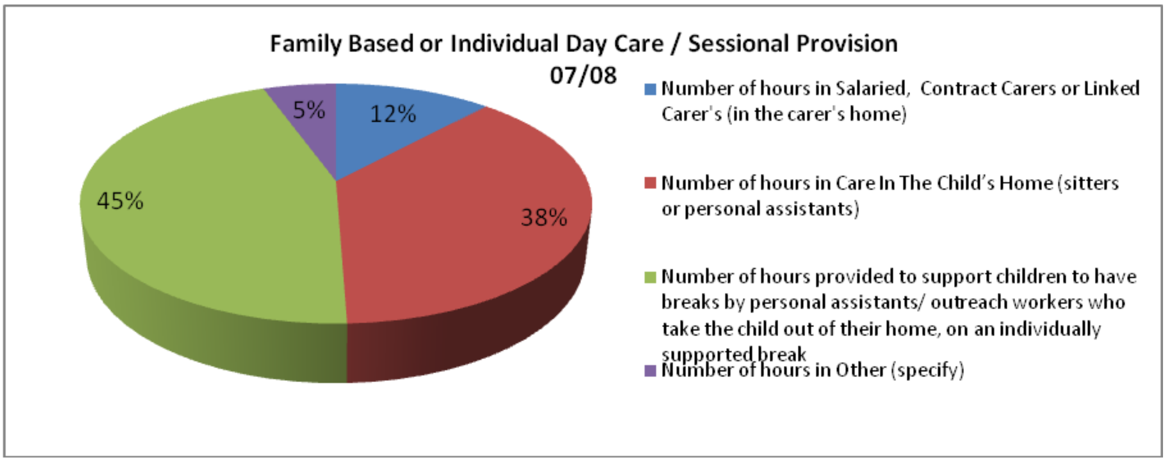


Table showing increases in family-based or individual day care/sessional provision (hours) from 2007/08-10/11

Family Based or Individual Day Care /Sessional Provision (Hours)	Actual 07/08	Actual 10/11	% Increase
Number of hours in Salaried, Contract Carers or Linked Carer's (in the carer's home)	420,800	758,962	80%
Number of hours in Care In The Child‟s Home (sitters or personal assistants)	1,330,042	2,327,361	75%
Number of hours provided to support children to have breaks by personal assistants/ outreach workers who take the child out of their home, on an individually supported break	1,596,221	2,920,068	83%
Number of hours in Other	195,236	609,773	212%
Total Number Of Hours	**3,542,299**	**6,616,164**	**87%**


Family Based or Individual Day Care / Sessional Provision
07/08
5%
12%
45%
38%
Number of hours in Salaried, Contract Carers or Linked Carer's (in the carer's home)
Number of hours in Care In The Child's Home (sitters or personal assistants)
Number of hours provided to support children to have breaks by personal assistants/ outreach workers who take the child out of their home, on an individually supported break
Number of hours in Other (specify)

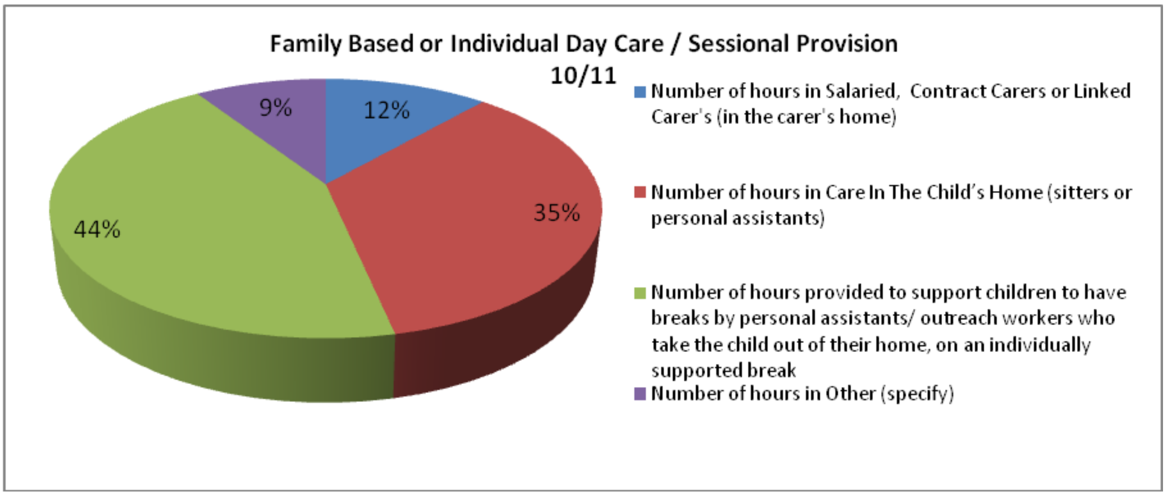
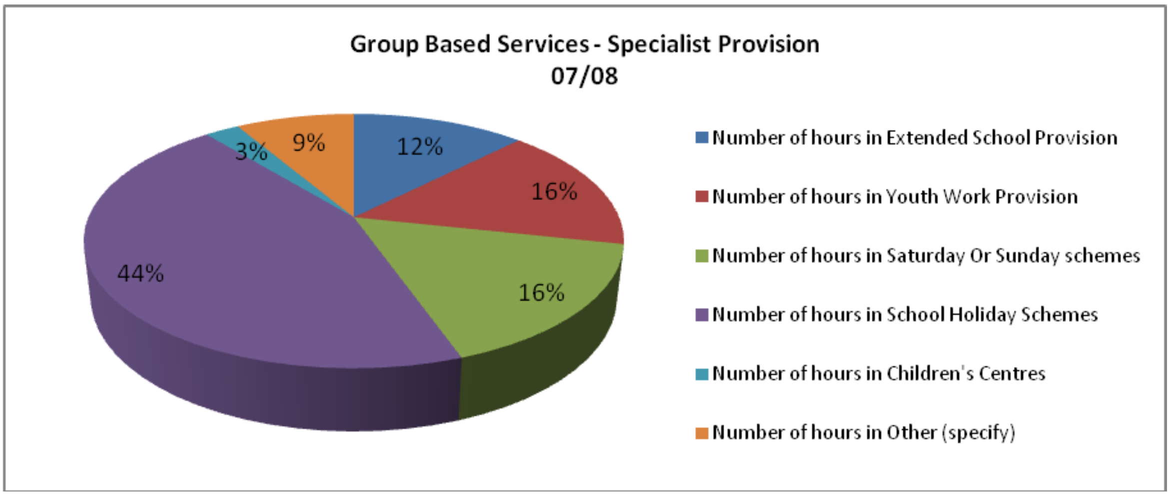

Family Based or Individual Day Care / Sessional Provision
10/11
9%
12%
44%
35%
Number of hours in Salaried, Contract Carers or Linked Carer's (in the carer's home)
Number of hours in Care In The Child's Home (sitters or personal assistants)
Number of hours provided to support children to have breaks by personal assistants/ outreach workers who take the child out of their home, on an individually supported break
Number of hours in Other (specify)

Table showing increases in group-based services - specialist provision from 2007/08-10/11

Group Based Services - Specialist Provision	Actual 07/08	Actual 10/11	% Increase
Number of hours in Extended School Provision	236,605	919,712	289%
Number of hours in Youth Work Provision	303,312	876,247	189%
Number of hours in Saturday Or Sunday schemes	308,125	850,164	176%
Number of hours in School Holiday Schemes	846,101	1,727,244	104%
Number of hours in Children's Centres	46,988	201,817	330%
Number of hours in Other	161,725	649,496	302%
Total Number of hours of group based Specialist Provision	**1,902,856**	**5,224,680**	**175%**



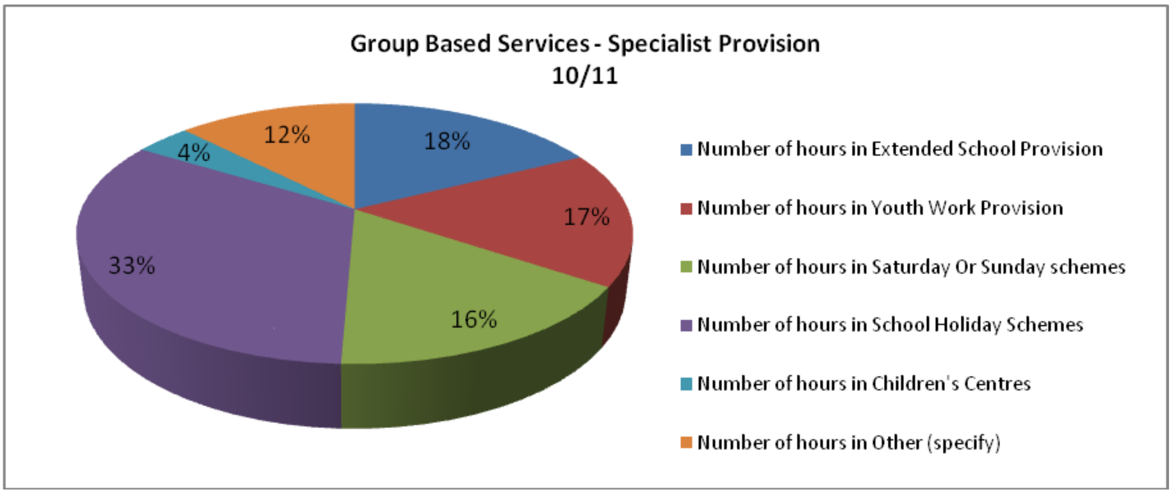
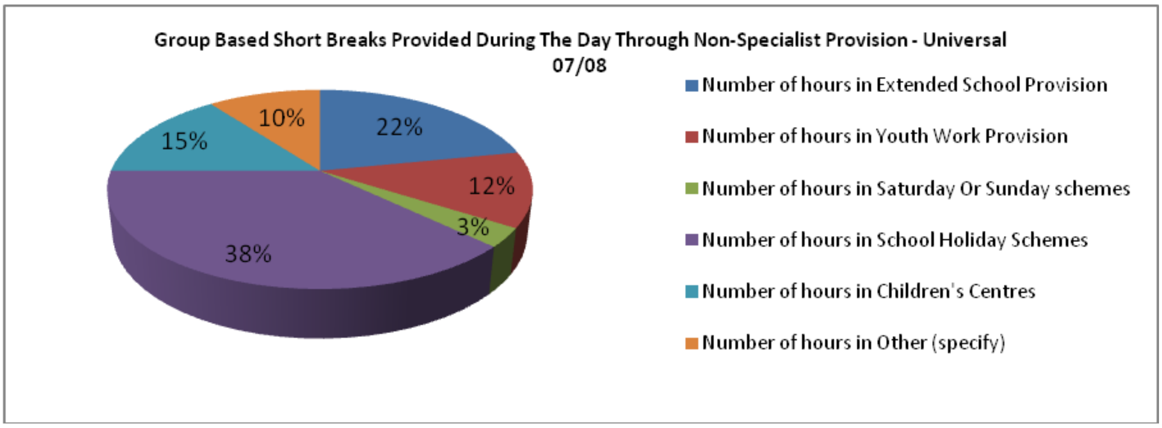
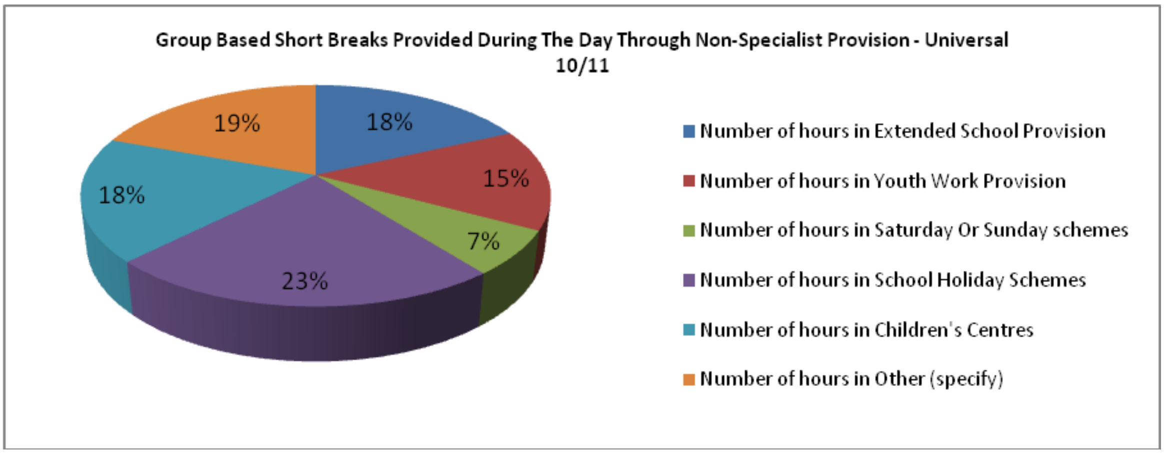


Table showing increases in group-based short breaks provided during the day through non-specialist provision - universal (hours) from 2007/08-10/11

Group Based Short Breaks Provided During The Day Through Non-Specialist Provision - Universal (Hours)	Actual 07/08	Actual 10/11	% Increase
Number of hours in Extended School Provision	138,602	446,706	222%
Number of hours in Youth Work Provision	77,358	364,555	371%
Number of hours in Saturday Or Sunday schemes	19,457	159,981	722%
Number of hours in School Holiday Schemes	240,504	571,120	137%
Number of hours in Children's Centres	93,512	446,699	378%
Number of hours in Other	65,093	478,378	635%
Total number of provision hours	**634,526**	**2,467,439**	**289%**


Group Based Short Breaks Provided During The Day Through Non-Specialist Provision - Universal 07/08
22%
12%
3%
38%
15%
10%
Number of hours in Extended School Provision
Number of hours in Youth Work Provision
Number of hours in Saturday Or Sunday schemes
Number of hours in School Holiday Schemes
Number of hours in Children's Centres
Number of hours in Other (specify)


Group Based Short Breaks Provided During The Day Through Non-Specialist Provision - Universal 10/11
18%
15%
7%
23%
18%
19%
Number of hours in Extended School Provision
Number of hours in Youth Work Provision
Number of hours in Saturday Or Sunday schemes
Number of hours in School Holiday Schemes
Number of hours in Children's Centres
Number of hours in Other (specify)

Appendix II - How programme objectives link to the Full Service Offer (FSO)

Programme Objective 1: Base service provision on the identified needs of eligible disabled children/ young people and their families

- **FSO 1**. Be based on a needs assessment of the local disabled child population, taking into account the voice of disabled children, young people and their families
- **FSO 6**. Be culturally appropriate and meets the racial, cultural, linguistic and religious needs of disabled children and their families

Programme Objective 2: Significantly increase the volume and range of short breaks

- **FSO 2**. Offer a significantly greater volume of short breaks provision set against a 2007-2008 baseline, and which reflects the additional funding levels available from Government
- **FSO 4**. Offer a wide range of local short breaks provision, tailored to families needs and including:

a) Support for disabled children and young people in accessing activities in universal settings, delivered through the following:

i) The support of a befriending, sitting or sessional service
ii) Measures that build the skills of universal service providers
iii) Measures specific to severely disabled children that are undertaken to meet their physical access requirements in universal settings (DDA plus)

b) Overnight breaks, with care available in both the child's own home and elsewhere

c) Significant breaks during the day, with care available in the child's own home and elsewhere

Programme Objective 3: Significantly improve access to short breaks provision

- **FSO 3**. Use fair, understandable and transparent eligibility criteria that enable short breaks to be used as a preventative service and which do not restrict provision to those threatened by family breakdown or other points of crisis

- **FSO 7**. Ensure that provision is available on a planned and regular basis and at the times when families and young people need breaks - this should include evenings, weekends and holiday provision, and have the capacity to respond to urgent care requirements

- **FSO 8**. Provide age-appropriate provision which ensures that children/young people in priority groups are not disadvantaged in accessing short breaks

- **FSO 10**. Promote information about available provision to the public, including details of eligibility - including threshold criteria - and routes to accessing the service

Programme Objective 4: Improve the quality of short breaks provision

- **FSO 5**. Provide positive experiences for children by promoting friendships and by encouraging social activities, new experiences and supportive relationships with carers

- **FSO 9**. Utilise the service provider that offers the best possible combination of skills and experience to deliver services of the highest possible quality to meet individual needs at the most efficient cost

Short break services are **additional services** required to support disabled children and their families; over and above the universal services expected and available to all families. The issue of „additionality‟ is important.

Appendix III - Short Break Service Models

1. Overnights

The child sleeps away from home overnight or is cared for in own home and the responsibility for caring is taken over from the main carer for a determined period. Usually, but not necessarily, an overnight stay would be for a 24-hour period. No short break stay should exceed 28 days continuous care.

Overnights can be provided in a number of settings:-

- **Residential Short Break Unit -** these are specialist units specifically to provide overnight stays and may be provided by local authority or voluntary organisation
- **Hospices –** provided by either health sector or voluntary organisation, these units offer short breaks or longer term support to children with complex health care and palliative care needs
- **Family-based** – provided in the home of a contract carer - also known as fee paid, salaried, professional or link-plus carers. They are approved foster carers who provide short breaks „on a full-time‟ basis and receive a fee or salary throughout the year, even when they do not have a child in placement. In addition, they usually receive an allowance when a child is in placement in the same way as other short break carers. Sitters and personal assistants are usually employed on a casual self-employed basis and are paid a salary or hourly fee rather than an allowance
- **Child's own home** – care can be provided by a domiciliary care worker, contract carer, sitter or personal assistant. To be a short break, the main carer must be

able to leave the home if they wish and responsibility for caring is entirely with the paid carer

- **Other** – includes all other settings commissioned to provide overnight stays and the types have increased over course of the programme to include: camping trips, residential school trips, youth club residential, holidays. If a carer accompanies the family on holiday to care for the child, the provision is included in this category, as long as the main carer is able to have a full break from caring

2. Family-based or individually supported daytime short breaks

Family based day care services are short breaks provided by an approved carer that do not involve an overnight stay in the home of the carer or the child.

Settings:-

- **Family-based day care –** some foster/contract carers will provide support in the daytime only
- **Child's own home** – provided by sitters, foster carers or personal assistants for an agreed time
- **Individual support outside of own home** – a personal support worker cares for the child for an agreed period and supports them in various activities
- **Other** – individual day support provided in any other setting that does not include above, more often provided in residential unit but not overnight

3. Group-based specialist short breaks and group-based non-specialist

Short breaks are provided sessionally in settings with other children. Specialist settings are those that cater for disabled children only and non-specialist are those accessible to all children, regardless of ability. Most of group-based provision takes place in universal services but some may be specialist only.

- Extended School services –after-school or pre-school activities;

- Youth work – group sessions for older children and young people specifically, usually above the aged of 13
- Saturday or Sunday schemes – sessional group provision at the weekends
- School holidays – sessions provided especially for the school holidays
- Children‟s centres – sessions provided in children‟s centres
- Other settings – any other settings where group sessions are provided e.g. sports trips that do not fit into any other category

Universal services

Universal services are those services provided to all children, young people and their families, such as children‟s centres, youth clubs, extended school activities and child care.

All universal services have a duty to respond to the Disability Discrimination Act by ensuring that their services are accessible to disabled children and young people.

Appendix IV – TDC Products

Readiness Criteria Standards: Guidance for Local Area Assessment and Tracker Completion - February 2009

Transforming Short Break Services – an introduction - Version 1.1 March 2009

Short Breaks Capital Programme: Planning and Practice - Version 1.0 May 2009

Short Break Learning Sets - Version 1.0 May 2009

Transforming Short Breaks: What information do we need and how should we use it? - Version 1.1 June 2009

LAIMP Guidance - Updated June 2009

Adopting an Outcomes Approach - Version 1.0 July 2009

Developing the Market for Short Breaks - Version 1.0 August 2009

Planning and Developing the Short Breaks Workforce - Version 1.0 October 2009

Developing Effective Joint Working between Health and local Authorities - Version 1.0 October 2009

Facilitating Integrated Practice between Children's Services and Health - Version 1.0 November 2009

How to implement a Successful Short Breaks programme - Version 1.0 November 2009

Impact of the Short break programme on the Prevention of Disabled Children Entering the Looked After System - Version 2.0 January 2011

Impact of Aiming High for Disabled Children on the Development of Family Based Short Breaks - Version 1.0 February 2011

Access TDC products via the National Archives: http://webarchive.nationalarchives.gov.uk/20110302114019/togetherfdc.org/default.aspx