

Short breaks for disabled children

Briefing Papers Pack

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 and are available on the DfE Publications website. The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short breaks provision and the experiences of children, young people and families. This series of briefing papers was produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

This pack contains all four Briefing Papers



Contents

	Page
Briefing Paper No. 1 – Commissioning	5
Briefing Paper No. 2 – The Range of Short Breaks	11
Briefing Paper No. 3 – Family Participation	17
Briefing Paper No. 4 – Personalised Funding	23

Acknowledgments

CeDR and NDTi would like to offer special thanks to the families that took part in the research, the workers in Local Authorities who facilitated our access to families and to the Department for Education who commissioned the evaluation. The views presented here are those of the authors and not the Department for Education.

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Short breaks for disabled children

Briefing Paper No. 1 – Commissioning

The purpose of this Briefing Paper

This is one of a series of briefing papers produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 [1-4]. The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short break provision and the experiences of children, young people and families.

This Briefing (No 1 of 4) considers specific commissioning actions that can result in improved outcomes.

Definition of the issue

The purpose of commissioning is to ensure that resources are used effectively to achieve policy aims and thus the best possible outcomes for people who use services. Although in practice much commissioning has focused simply on procurement, it needs to be a wider process that also strategically influences the way in which services are provided and the range of options available.

What does Government policy say about commissioning?

- The NHS reforms will provide new mechanisms for PCT clusters and those involved in commissioning children's health services to review commissioning arrangements. New Health and Wellbeing Boards will provide a forum for discussion of local need.
- As in other areas, short breaks policy has strongly promoted the involvement of people who use or who may use services in the commissioning process, with the aim of providing services which are more responsive, innovative and tailored to family requirements [5, 6]. Family members can, for example, be involved in identifying local needs, planning, identifying and selecting providers, formulating contracts and evaluating the services provided.
- Current policy also promotes partnership working between commissioning bodies; for example between local authorities and health services through joint needs assessments, shared strategies and joint commissioning [5, 6].

- Short breaks policy encourages commissioning bodies to build strong and supportive relationships with local service providers, to formulate clear and proportionate contracts and to specify precise requirements for service delivery, the outcomes to be achieved and how the service will be reviewed and evaluated [5, 6].
- Each local authority is required to prepare and publish by 1st October 2011 a 'Short Break Services Statement' [5, 7] which outlines what services are available, how eligibility is decided and how decisions about the range of services was decided. Local authorities' approaches to commissioning will be a key part of this statement.
- The development of personal budgets or direct payments is one way in which the commissioning of short breaks may be performed by families themselves, reflecting their personal choices and specific requirements [5, 6].

What the Short Breaks Evaluation found out about commissioning

Almost all local authorities and partners were pursuing the same policy objective - to shift their short breaks provision from residential, high-cost, low-volume services to smaller scale provision and flexible packages of care. However their progress in doing so varied considerably and their pace of change was often a reflection of their approach to commissioning these services. Summarised below are the core components of those 'successful' Pathfinder sites where a considered approach to commissioning was helping develop the provision of short break services which were more flexible, creative, individually orientated and cost effective.

- **A clear vision from the outset of the overall aims for the short break service and the strategic steps required to achieve those aims.** For example one Pathfinder identified the following: simplifying access to support; maximising the control young people and their families had over their lives and the resources allocated to them for support; reducing dependence on specialist services; and improving 'life' outcomes by promoting and enabling inclusion in community activities. The most successful sites were those where there was strong leadership (often one key individual) in the creation and subsequent communication of this vision.
- **The creation of a robust analysis and understanding of current and projected population needs,** informed by local registers (e.g. one Pathfinder had a well developed register of children and young people with disabilities cross referenced with the SEN register plus national data and numbers under 18 claiming DLA). In addition, conducting an analysis of existing services in terms of usage and costs enabled authorities to assess the effectiveness and value of their services in seeking to meet those needs and enabled the subsequent identification of gaps in provision.
- **Regarding parents as core partners in all stages of the commissioning process.** For several Pathfinder sites this approach was at the core of their vision for service change. One site transformed their historical approach from minimal engagement to full involvement of parents by ensuring families made up 50% of the Commissioning group, represented the Short Breaks team at meetings (including with Government), chaired conferences and so on. One parent commented '*parents are no longer told there is no service, we are now being asked about needs and changes, looking at outcomes instead of outputs.*' Without fail all Pathfinder sites which involved parents as equal contributors could identify clear benefits

to their decision making processes in terms of relevance, understanding, and identifying barriers to achieving successful outcomes. Those Pathfinders who struggled to do so successfully were generally willing but often failed to recognise the importance of proactive support to set up the appropriate structures, the need to develop and nurture these groups, the associated costs in doing so (both in terms of direct resources and officer time) and the importance of ongoing commitment to that process.

- **Ensuring a joined up collective approach to the vision with the active engagement of local partners,** such as the NHS, voluntary and independent sector providers, mainstream services and parents. One Pathfinder site held ‘launch days’ to present and discuss their overall plans with different interest groups, resulting in mixed working groups to develop the detail, culminating in the final strategic plan. Representatives of these groups subsequently formed the main group overseeing the ongoing implementation of the plan and the delivery of the desired outcomes, as identified and refined by the initial working groups.
- **Embracing the expertise and knowledge of service providers from both the voluntary and private sector in the commissioning process.** Whilst some authorities preferred to keep the commissioning and provider sides quite distinct, the evaluation identified that the most impressive progress was being made where there was close working and a true sense of partnership between commissioners and providers. This enabled the commissioners to utilise the breadth of experience of providers to help ensure (for example) decisions were rooted in realistic expectations in terms of services, timescales, costs and outcomes. One Pathfinder site held ‘market testing days’ where providers and parents collectively discussed and debated the proposed service specifications to test viability and relevance. This often resulted in partnership arrangements (rather than competition) between voluntary providers who felt they could meet the specification more effectively by working together. Once contracts had been awarded this same site continued to meet monthly with providers to monitor progress, identify barriers and work together to improve and smooth the processes. Several providers commented on the immense value of this constructive relationship *‘other Authorities just want to provide services, they are getting their teeth around outcomes...this is new for them too so it is great to work in partnership working out how we can help each other move forward.’*
- **Cascading the message consistently and clearly through organisations** was equally important, in particular securing the ‘buy in’ of existing staff to alternative approaches and the reasons for doing so. Overcoming cultural or traditional ways of working was often a challenge and in several instances ‘new’ teams or posts were created to work alongside existing services to deliver short breaks in alternative ways. This often proved to be a difficult transitional process but over time it was hoped/anticipated that these two ways of working would gradually become much more integrated.
- **Identifying the desired outcomes for short break services and setting up systems at the beginning of the planned changes to measure the impact of these services and evaluate their effectiveness.** Demonstrating the value and cost effectiveness of the new services is absolutely essential to the future development of short break services, yet almost all Pathfinder sites had struggled to put any systems in place to enable them to do so. Only one site had established a performance framework for their newly established community team which linked the specific outcomes identified for the family to the use of resources i.e. the costs of the support package required to deliver those outcomes. This was applied on an individual basis (e.g. measurable and meaningful outcomes such as two unbroken nights sleep a week

for parents or a child to have made two friends by November). Such information could then be collated and analysed across a range of fields such as age, geography, and costs of services. Another site had begun to identify individual outcomes for the children as they accessed different services, resulting in children being 'progressed on to' different services as their outcomes were achieved. However this was not without opposition from some parents who preferred their children to remain within specific services with which they were most comfortable.

- **Utilising evaluation and feedback to influence and change the commissioning process.** Most Pathfinder sites had some forms of feedback from parents and young people in place however minimal, but it was often hard to see how this information fed back into the planning structures and the extent to which their views had significantly influenced existing and future services. This relationship was much more evident where parents were actively engaged in the commissioning structures as they would often play a part in the gathering of this information and would ensure it was used constructively.
- **Engaging new, alternative providers.** This was a challenge for many sites where provision tended to be concentrated on established specialist providers, but without exception authorities wished to develop a broader range of provision. To attract new providers a range of approaches had been adopted:
 - Proactive contact with potential providers, often of mainstream services, offering support and training both initially and on an ongoing basis;
 - A review of procurement procedures in an attempt to: reduce the quantity of paperwork required to ensure it was more proportionate with the size of the contract; implement manageable timescales to allow for CRB checks etc; and recognise the financial pressures on small organisations and the need to pay for contracts in a reasonable timescale.

Developing this approach was particularly important when commissioning individualised support for families. Many sites had created posts such as short break co-ordinators who worked with individual families and sought to purchase the most relevant and enjoyable short breaks for the family and child from a diverse range of mainstream and specialist providers. However enabling this process to take place smoothly and effectively was a challenge in many areas as co-ordinators came across bureaucratic barriers to procuring one-off activities in mainstream services. One manager commented '*the more creative we are the heavier the bureaucratic process behind it all.*' A number of sites had addressed this by setting up an 'inclusion grant', funds which could be accessed quickly and easily to get extra support for a child to access a diverse range of activities.

Checklist for Effective Practice

From this evidence, a series of inter-connected commissioning actions can be identified that – if implemented in a coherent and integrated way – are likely to result in significantly improved services and outcomes.

Effective practice to improve short breaks will involve the commissioning function:

1. Leading the development of a clear strategic vision and the steps required to achieve that, whilst paying attention to this being developed by (and having the support of) all key partner agencies, in particular families.
2. Creating a system that offers a robust analysis and understanding of current and projected population needs through using and/or developing local registers.
3. Conducting an analysis of the usage, costs and impact of short breaks (particularly as judged by families) to help understand the effectiveness and value of these services and identify gaps in provision.
4. Adopting a culture of seeing parents as full partners in the commissioning and delivery process and investing the time and resources to enable this to happen.
5. Taking action to ensure a joined up collective approach with the active engagement of local partners, such as the NHS, voluntary and independent sector providers, mainstream services and parents.
6. Recognising providers as key partners and involving them in service planning and design – creating systems and structures that enable this to happen in an open and non-competitive way.
7. Ensuring a communication strategy that promotes a wide understanding and buy-in of the new ways of working that are expected – including by investing in appropriate leadership and skilled staff to lead this work.
8. Developing outcome measurement systems that are genuinely about the experiences of children, young people and families rather than service processes, and linking those to resource allocation decisions in order to increase the impact of available resources and to be able to evidence value for money.
9. Utilising outcome-focused evaluation evidence and consumer feedback to influence and change commissioning decisions and openly demonstrating this to parents and other stakeholders.
10. Engaging new, alternative providers including a focus on mainstream, community organisations and adapting commissioning processes to facilitate entry to the market by smaller providers.

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Short breaks for disabled children

Briefing Paper No. 2 – The range of short breaks

The purpose of this Briefing Paper

This is one of a series of briefing papers produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 [1-4]. The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short breaks provision and the experiences of children, young people and families.

This Briefing Paper (No 2 of 4) highlights a number of actions and outputs that can result in improved outcomes.

Definition of the issue

The term ‘short breaks’ is used to describe a wide range of services for disabled children and their families including those which have often been referred to as ‘respite’. Having a wide range of short breaks available is important because of the diversity of families who need to use short breaks [3]. Short breaks services can differ significantly on a number of dimensions, including: the duration and timing of the break, the type of activity involved, the location or setting for the break, who provides the break, how the break is organised, and whether the disabled child or the wider family take part.

In this briefing paper we summarise evidence about how families have benefited from a wider range of short breaks and describe what would be effective practice in this area.

What does government policy say about delivering a range of services?

- Recent increases in resources allied to policy trends have resulted in the range of short break services offered to families becoming more diverse[5].
- The Department for Education [6] has outlined its aspiration to make a wider range of short breaks available as part of its aim to increase parental choice and to meet the needs of families with disabled

children. In addition continued investment of over £800 million between 2011 and 2015 as part of the Early Intervention Grant has been announced.

- Regulation four of the Breaks for Carers of Disabled Children Regulations 2011 [7], which came into force on 1st April 2011, stipulates that local authorities have a duty to provide a range of services that will assist carers in continuing to provide care or in providing care more effectively. The range of short break services that are identified in the legislation are:
 - day-time care in the homes of disabled children or elsewhere
 - overnight care in the homes of disabled children or elsewhere
 - educational or leisure activities for disabled children outside their homes
 - services available to assist carers in the evenings, at weekends and during the school holidays
- Advice provided by the Department for Education [8] to support local authorities in implementing these duties contains a clear statement that local authorities have a duty to provide a range of services which will:
 - ensure that the needs of different types of carers are taken into account
 - be available as needed during the day, night, at weekends and during the school holidays
- This advice states that as well as providing a range of short break services, local authorities must publish a statement of their short break services by October 2011. This statement should include how the range of services provided by the local authority will meet the needs of families with disabled children in their area.
- Furthermore, local authorities should work in partnership with health services to ensure that they understand the range of short break services in their area.

What the Short Breaks Evaluation found out about delivering a range of short break services

Local authorities and partners were delivering a range of short breaks services, aiming to address the diverse needs of the populations that they served. In most local authorities this provision was accompanied by ongoing efforts to establish and respond to the expressed needs of these populations. In some local authorities additional efforts were being made to investigate the needs and aspirations of groups or communities that were felt to have been less well served previously, such as minority ethnic communities or certain age groups of children.

The successful Pathfinders undertook the following to support the provision of a range of short breaks:

- **Pathfinders developed a range of short breaks based on an implicit objective of promoting resilience in the family unit, as a whole.** It was seen to be imperative to develop a range of options which might be

targeted at different family members, including siblings and extended family; *what works for Mum may not prove helpful to Dad*. Successful Pathfinders ensured that options were available for soft-play and outdoor recreation for pre-school as well as supporting teenagers to get together at an evening youth group, either to take part in something active and healthy or simply make new friends and having some fun worrying the staff by doing something unhealthy!

- **Pathfinders actively listened to the views of young people and their families** when planning (and commissioning) the range and type of services that were delivered. In this 'listening' the successful Pathfinders also made interesting and new suggestions about activities or experiences that were perhaps beyond the envisaged expectations of disabled young people and their families. Most Pathfinders supported some form of annual parent forum which provided opportunities to discuss short breaks and gather views and experiences. In one such forum, parents were asked to vote for their favoured option from a menu of potential developments in their locality. Another Pathfinder worked with a group of young adults who had direct experience of receiving short breaks to undertake an extensive piece of market research with young people in schools. The findings from this research were used to inform the shape of service provision that was subsequently developed.
- **Pathfinders found that a flexible, perhaps less prescriptive commissioning process enabled 'new' providers to put forward suggestions** and proposals that were informed by their extensive experience with the wider community. Often such non-traditional providers came with fresh ideas and perspectives and both energised and challenged existing providers. In one Pathfinder, for example, a number of mainstream youth agencies found that they were able to offer a great deal of exciting community based activities to disabled young people. This included some challenging overnight trips away battling the elements on adapted bicycles, building muscles and character!
- **Pathfinders made a good range of options available and worked hard to ensure that individuals, families, groups and agencies were aware** of how to go about accessing these services quickly and easily, often without the need for an extensive assessment process. Pathfinders informed parents through newsletters, websites and information days and other events. Successful Pathfinders ensured that a wide range of health and social care practitioners were well informed about the emerging range of options available, and developed application or proportionate assessment processes that these practitioners could use to help families find a simple route into services. One Pathfinder used an annual carers event to host a 'market place' demonstration of the potential options in their area. Service providers presented colourful exhibits, photos and testimonies which highlighted what they had to offer and offered parents and practitioners the opportunity to find out more about each option and get a feel for what might work best for their son or daughter.
- **Pathfinders created and publicised opportunities for individuals, families and groups that went beyond the standardised list of options**. These opportunities might be secured using Direct Payments or a Personal Budget and many local authorities initiated a kind of 'participation' fund to meet specific or one-off needs and requests. Such funds might have paid, for example, for a dedicated worker to ensure that young people were able to take part in mainstream activities with their friends or siblings.

Most Pathfinders developed a funding system and support mechanism to enable families to enjoy a holiday together (with paid support) or a break apart. Other Pathfinders enabled parents and young

people to enjoy high quality short breaks through providing different forms of equipment such as wheelchair equipment, as well as more health related facilities. One Pathfinder provided an adapted tricycle for a young girl which both allowed her to play with her friends in the park and at the same time helped mum or dad to enjoy a well-earned sit down. Another Pathfinder provided one family with a laptop to help their son explore cyber space (safely) and leave his mum to catch up with other jobs or simply take some time for herself. In another area funds were used to buy a portable sports suite which featured a number of pieces of equipment adapted for wheelchair users.

- **Successful Pathfinders managed to present a balanced message concerning the nature of short breaks in their area.** This message both encouraged a flexible and creative re-interpretation of short breaks, whilst still being clear and straightforward with parents about new possibilities which went beyond traditional approaches to 'respite' care. In effect, the successful sites acknowledged that parents (and perhaps practitioners) could easily become confused about what was potentially available and therefore devoted significant attention to developing a clear and consistent message.
- **Pathfinders targeted a range of mainstream community services to help them to offer more suitable environments** for disabled young people and their family and friends. Successful sites devoted much time and energy to creating new partnerships with agencies that had not previously been closely involved with health and social care projects. In one site, for example, the Pathfinder team worked intensively in a project with a local leisure centre to assist them in developing a range of indoor and outdoor facilities and services that would be of great benefit. The involvement of the Pathfinder team further enabled the active participation of local disabled young people and their families in the overall development of the facilities. A number of new partnerships emerged which had the potential to improve mainstream services over and beyond the timescale of the Pathfinder pilot.
- **Pathfinders created streamlined, yet robust, systems to collect people's views about the strengths and limitations of the support services they had received.** These customer satisfaction tools were used effectively to shape future developments and to help to keep providers focused on delivering high quality outcomes.

Checklist for Effective Practice

From this evidence a consistent range of options or outputs emerged. Effective practice is likely to result in the following menu of options. Commissioners might benefit from comparing the range of options highlighted below with what is offered in their locality.

1. Availability - short breaks are offered:
 - During the day
 - During the evening
 - Overnight
 - During the weekend
 - Over more than one night
 - For short activities or breaks (1-2 hours)
 - For longer periods and perhaps days / trips away
 - Seasonally – particularly over summer holidays (play schemes) and other vacation periods

2. A range of settings are offered:
 - At home
 - In another family home or approved care worker / foster carers
 - In a school or 'after school' environment
 - Within an activity group organised by a community children's or youth agency
 - In the community taking part in individualised activities or experiences
 - Within an activity group that is targeted at a specific group, therefore offering specialist support and facilities
 - In a specialist residential facility

3. A range of activities are offered:
 - Sports and play
 - Music and arts
 - Friendship and socialising ('just chilling with my mates')
 - Getting out and about shopping, visiting, going to the cinema
 - Learning to speak up and developing confidence
 - Opportunities to meet others 'in the same boat', such as parents social events / meetings

4. Activities are offered to:
 - Individual young people
 - Groups of young people
 - Specific groups of young people e.g. people on the autistic spectrum
 - Young people and their siblings and friends
 - Parents with their children

- Parents without their children

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Short breaks for disabled children

Briefing Paper No. 3 – Family participation

The purpose of this Briefing Paper

This is one of a series of briefing papers produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 [1-4]. The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short breaks provision and the experiences of children, young people and families.

This Briefing Paper (No 3 of 4) highlights a number of actions which promote the full participation families in the provision of short break services.

Definition of the issue

Family participation in short break services for disabled children has tended to mean involving families in processes and decision making associated with the assessment and provision of their own short break services and a wider role in shaping the development of short break services in their local area. This briefing is intended to provide evidence based advice about how effective family participation in short break services provision can be achieved.

What does government policy say about family participation?

- Regulation five of the Breaks for Carers of Disabled Children Regulations 2010 [5], which came into force on 1st April 2011, states that local authorities have a duty to publish and regularly review a 'short break services statement'. This statement is aimed at increasing family participation by providing families with information about how the range of available services will meet their needs, and making the eligibility criteria for these services clear. Furthermore, local authorities must take the views of carers, disabled children and young people in their local area into account when preparing and reviewing their statement.
- Non-statutory advice [6] about implementing the regulations goes further, stating that local authorities should ensure that those who use short break services have the opportunity to shape service development and that they should receive feedback about the outcomes of any consultation in which

they are involved. The advice goes on to note that participation is more effective when there are structures in place (e.g. parent forums) to support it.

- Local authorities are also reminded that they should try to reach groups of parents who they may find difficult to engage, and that a failure to do so could lead to wider inequalities. To support this aim, local authorities are advised that they should monitor how far the disabled children and their families using short break services match the profile of disabled children within their local area [6].
- The green paper on special educational needs and disability [7] acknowledges the importance of family participation for improving short break provision. It also highlights the ways in which family participation can lead to parents exerting more control over the services they use, resulting in local authorities planning and developing short breaks that are cost effective and responsive to local need.
- Two actions associated with increasing family participation are outlined in the green paper:
 - Increasing access to personal budgets so that families can choose services that meet their needs.
 - The 'short breaks services statement' (discussed earlier) to be published by local authorities, which gives parents access to information about provision in the local area and the preparation and review of which must take into account families' views

What the Short Breaks Evaluation found out about family participation

Family participation was a central concern for all Pathfinder sites, yet the extent to which this had been achieved in any meaningful way or subsequently influenced the delivery of services varied considerably. Without question the historical structures and relationships at the commencement of the Aiming High work significantly impacted on the progress of the various sites; i.e. where good communication mechanisms were already in place this had created a sense of trust and confidence. However, more important was the extent to which sites embraced the concept of family participation and what they had done to put this into practice. Summarised below are the core components of those 'successful' sites where their commitment to family participation had been sufficiently thought through and implemented. This had resulted in more effective engagement of parents in both overall and individual commissioning processes, and the development of innovative short breaks which addressed local needs and utilised local community groups and resources.

- **Widespread commitment** from all key partners to engage with parents, accompanied by the recognition that to be effective, this will require **infrastructure support and investment**; in particular the need to ensure officers are available and willing to: talk and meet with parents; help set up and support parents' meetings; distribute information; provide venues; help as required with the distribution of information/newsletters; and meet expenses. This often requires a proactive approach to demonstrate commitment and develop momentum and then ongoing support to help maintain and nurture these new relationships.
- **The commitment to family participation should be reflected in the structures and processes** created for planning and developing short break services. For example several Pathfinder sites sought to have parents as at least one third of the members of their commissioning board. Another site ensured the first agenda item of the senior multi-agency planning group was issues identified by children and young people and the second item was issues identified by parents. Other Pathfinder sites involved parents in all aspects of the commissioning process, including planning days, 'market testing meetings' with providers and involvement in the quality components of contract monitoring. Senior officers reported

'they keep us very grounded...they keep us honest and on our toes...hold us to account...it is a very healthy relationship.'

- **Acting upon and responding to issues raised by parents.** No parent has time to waste and those interviewed were clear that there needed to be purpose and focus to their involvement. In the most successful Pathfinder sites parents felt their views were taken seriously, that they were treated as equals and that they could genuinely influence the decisions taken. Being able to evidence that actions and decisions had changed because of the input from families was an important way of building confidence and giving families a reason to give their time to partnership processes. Parents lost interest rapidly if their participation was felt to be merely tokenistic. *'We do have to feel like something is happening as a result of this. We are not a talking shop. We know it's difficult and money is tight. We just want people to be honest and open. Us parents have loads of ideas –we got a letter back after the meeting telling us what they were trying, that meant a lot.'*
- **Proactive commitment to family participation is extended throughout the organisation(s)** to ensure that those staff responsible for the planning and delivery of individual support packages work very closely with families in listening and responding to their individual needs. All the evidence from the pilot sites demonstrated that where there was an overarching demonstrable philosophy of working closely with parents this was reflected in front-line services and resulted in individually tailored support packages using diverse local services. One parent commented *'We are being listened to –such a breath of fresh air –they are listening to us and trying to meet our needs'*. Where parents felt commitment to active engagement was merely rhetorical with little substance, staff on the front line tended to be less flexible and responsive with support packages tending to be provided using mainstream traditional providers rather than being innovative and inclusive.
- **Commissioning processes encourage and support family engagement.** Several Pathfinders had begun to recognise the value added by involving parents in the overall approach to commissioning. For example one authority specifically required providers to demonstrate how parents would be involved in their delivery and monitoring of services and another worked with a group of parents to identify ten 'success criteria' to apply when evaluating new bids. With decisions around individual services, it is also vital to ensure that staff work directly with families to access individually appropriate support packages which respond directly to those needs identified by the family. Such approaches can prove to be a challenge when working within the confines of more traditional commissioning arrangements (and an over-reliance on panels to allocate resources). Ways of addressing this included setting up an 'Inclusion Grant' which employed a very short form to access extra support and could be allocated at team manager level; and creating a new team to work very closely with families, identifying their strengths and support networks and seeking to meet the gaps by using mainstream services that were implemented at no extra cost.
- **Expectation of providers to respond to parents' needs.** Once the commitment to family participation is overt and understood this needs to be reflected in the approach of all providers –as one Pathfinder site commented it *'raises the game across the board'*. Parents commented, *'The changing attitude of providers is very exciting, the message is really getting out there. There is a complete shift from why they can't to how can we support them to do this.'*

- **Creating an environment which responds flexibly according to the needs of different parents.** The significance of creating the right structures for engagement has already been referred to but it is also important to recognise this will mean doing things in lots of different ways. Regular meetings are not convenient and do not work for all families. Opportunities also need to be created via email or online forums and larger less frequent consultation events, enabling a wider range of parents and children/young people to participate. Strategies for establishing meaningful contact with 'hard to reach' parents, particularly those from Black and minority ethnic communities are sometimes challenging, with ideas that appear to have an impact including appointing individual workers or commissioning an independent organisation specifically to engage with their hardest to reach communities.

Checklist for Effective Practice

From this evidence, it is clear that in order to be effective the commitment to family participation must be recognised and endorsed throughout the organisation in order to result in meaningful engagement and improved outcomes.

Effective practice to improve short breaks will involve Local Authorities recognising the need to engage families by:

11. Demonstrating widespread commitment to working with families and investing in an infrastructure with dedicated resources to facilitate and support this engagement on an ongoing basis.
12. Creating structures and working arrangements which reflect this approach that are designed to ensure families have the opportunity to contribute to all aspects of the planning and delivery of services - approaches that consider the best mechanisms for people's voices to be heard.
13. Actively listening to the issues raised and responding sensitively and appropriately, acting upon the issues wherever feasible, telling people what has been done with their views and, where opinions are not taken on board, communicating and explaining the reasons why not.
14. Ensuring the commitment to working closely with families is reflected and acted upon throughout the organisation.
15. Involving families in all stages of the commissioning process and enabling front line staff to access individual support packages without recourse to bureaucratic processes.
16. Challenging providers to involve families in the monitoring and evaluation of their services.
17. Reaching out to the harder to reach families, especially those in Black and minority ethnic groups, by working with dedicated workers or other voluntary organisations to facilitate communication and understanding.

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Short breaks for disabled children

Briefing Paper No. 4 – Personalised Funding

The purpose of this Briefing Paper

This is one of a series of briefing papers produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 [1-4]. The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short break provision and the experiences of children, young people and families.

This Briefing (No 4 of 4) is concerned with personalised funding for short breaks.

Definition of the issue

Families with disabled children are being offered an increasingly wide range of different types of short break service; even so it is recognised that each family's circumstances are unique and it is difficult to provide services that perfectly meet everyone's needs. Over recent decades there have been trends towards allowing people who use (or potentially use) public services to have a greater voice and greater control over the services they use. This briefing considers how various types of personalised funding are starting to be used to enable families to secure their own unique package of short break services. Different types of personalised budgets include Direct Payments (monies given to a family to buy a particular service) and other arrangements where families have control over resources that are managed by a third party.

Recent Government policy and personalised funding

- In 2009 the Government introduced updated regulations which required responsible authorities to offer direct payments in place of directly provided services for carers and children where the recipient was capable of managing the payment in a way that would meet identified needs [5].
- In the 2010 spending review the coalition Government announced their intention to significantly extend the use of personal budgets; suggesting that this would improve outcomes, promote efficiency, localise power, benefit groups of people including disabled people and help draw upon services provided by voluntary and community sectors [6].
- The Department for Education has provided advice for local authorities concerning personalised funding for short breaks [7] This advice re-states the requirement for local authorities to offer direct payments in lieu of short break services. The advice notes that more families are using direct payments and suggests

this provides positive outcomes such as greater choice and flexibility, access to community resources, expansion of the short break workforce and improved access for children with rare and complex conditions.

- The advice also outlines the support that needs to be given to help families understand and use direct payments effectively. This advice also states that the short break services statement required to be published by local authorities should highlight the support available and give consideration to the balance between direct services and direct payments.
- In its Green Paper the coalition Government sets out plans to extend access to personal budgets for all families with a child with a Statement of Special Education Needs or the new Education, Health and Care plan by 2014 [8]. These personal budgets could pool various funding streams and could enable families to secure various care, health and education services.
- The Green Paper proposes support for families through Key Workers who will help 'navigate' the range of services on offer and cites evidence that with good support families are able to manage and control payments and will change providers in order to find services which offer better performance and quality.
- The Green Paper acknowledges that personal budgets would be unsuitable in some service areas where collective commissioning provides greater efficiency or protection for service users.

What the Short Breaks Evaluation found out about Direct Payments and Personalised Funding¹

a) Creating the right conditions for Direct Payments and Personalised Funding

New initiatives and innovations such as Direct Payments take time, energy and thought to implement effectively, especially when they involve sums of money being paid directly to citizens in respect of an individual's disability. Lead officers in Pathfinder sites that had made progress in using direct payments appreciated that their introduction necessitated a change in culture and thinking, as well as simply applying new processes. These Pathfinders focused on a number of interrelated tasks which they hoped would create the right conditions for the expansion of Direct Payments thereby aiming to achieve necessary changes in culture and thought.

First, Pathfinders ensured that Direct Payments were central to their overall short breaks strategy and invested much time and energy in ensuring that key managers were empowered to lead and implement such strategies and policies. This meant, for example, making information, training and advice available to social work managers and their teams as well as ensuring that managers were clear about the resources (budgets) that were available. Successful Pathfinders encouraged social work teams to operate as creatively as possible in responding to the situations of individual young people and their families. They acknowledged and understood that success was about winning over 'hearts and minds' as much as it was about providing robust systems.

Secondly, successful Pathfinders made significant efforts to produce clear and coherent information about Direct Payments and the opportunities that were now available to families. This information was presented in a number of different formats, from traditional leaflets to website pages and links. Parents and families were also invited to learn more about direct payments through presentations at meetings and parent / carer forums. These often included parents themselves sharing their own personal experiences of using direct payments and, for example, becoming an employer.

¹ At the time of the evaluation, the concepts of personal budgets had not fully taken hold in children's services with the exception of direct payments which was the only mechanism being used and talked about.

Thirdly, Pathfinders invested in an infrastructure to support people to make use of Direct Payments and personalised funding. For example, Pathfinders supported the creation and expansion of various forms of advice and support service. A number of these services had existed prior to the Aiming High initiative. These services or teams were either delivered by the local authority or, in other situations the local authority had commissioned an independent agency to deliver such services. These teams and agencies played a key role in delivering information, advice and guidance to families and often offered a comprehensive range of services including:

- Assistance with recruitment and selection of personal assistants
- Assistance with employer responsibilities
- Assistance with employment legislation
- Assistance with managing staff
- Assistance with payroll issues, tax and national insurance
- Assistance with supervision, appraisal and annual leave

It is clear that such support agencies were fundamentally important in helping families and individuals to become competent and confident employers. One mother commented, for example, on the problems she had encountered in identifying a suitable personal assistant and praised the support she had received during the recruitment process:

“It is difficult to find someone as you feel so vulnerable with your own child and own home...I had one lady who didn't work because they were lazy..., it was all so stressful, I don't know how I would have coped without the support organisation.”

Importantly, the evaluation (like other evaluations of direct payments) found that if this support was not available or time was not taken to build support for the concept of personalised support, then many families experienced direct payments as an additional burden that they did not wish to have, and the resultant benefits in terms of better outcomes for people were not then achieved.

b) Outputs and Outcomes

Direct Payments and personalised funding delivered positive outcomes for many young people and their families and led to the development of some flexible and innovative solutions that were welcomed by the majority of recipients:

- Through Direct Payments, young people and their families were enabled to develop their own support package that was flexible and adapted to their own unique needs and circumstances. Often it was the ability to choose the right personal assistant that brought this uniqueness. For example, one family were able to employ a personal assistant of similar age and youthful outlook to their daughter that meant their daughter was supported to get out and about doing things that teenagers wanted to do, but which parents or an older worker may not enjoy. In this situation it was not the quantity of hours per week that was most significant but the quality of the relationships that emerged.
- Direct Payments had enabled families to recruit and employ personal assistants who were known and trusted by the people concerned including for example, teaching assistants and extended family members. This control over choosing staff gave families added confidence and trust and on occasions resulted in short breaks being secured where alternative support had previously not been taken up. In

one example, a young boy who had experienced a life threatening heart condition was being supported by an extended family member. His mother was clear that he benefited from having a personal assistant who knew him well enough to let him enjoy the hurly burly of youthful play, without feeling overly restricted by any potential but unavoidable consequences.

- Direct Payments and personalised funding have enabled innovation by encouraging families to come up with more creative solutions than were previously possible. Perhaps families find it is easier to risk trying out new things when they are the ones making the decisions and identifying the potential pitfalls. For example, one family found that a great break for them was achieved by using a sizeable proportion of their budget to employ two workers to take their daughter to a local hotel for one night every couple of months. This delivered a quality of outcome that they had not been able to achieve through a number of other, shorter, less intensive, approaches.
- Direct Payments enabled families with very individualised (and often complex and expensive) needs and aspirations to access short breaks. This included some who had previously declined or not accepted support because they felt it was either too 'segregated' or stigmatising. One family, for example, which included two autistic teenage sons, had had poor experiences of specialist groups for disabled children in their area. However, Direct Payments had enabled them to employ personal assistants to support both of their sons to pursue a range of community and home based activities. In this instance, the complexities and challenges of daily family life could only have been addressed by flexible and responsive support underpinned by Direct Payments and family directed support.
- In other complex family situations, Direct Payments were being used to promote better balance and resilience among all siblings and parents. For example, one mother managed her personal assistant hours very flexibly to address the needs of all members of the family. Some of her hours were used to enable her disabled son to access community activities and allow her to spend time with her two other children, while the remaining hours were used to ensure that she was able to get some time to herself every week.
- Direct Payments enabled Pathfinders to deliver one off equipment or resource solutions to enable short breaks. For example, families were supported to buy computers, sports and play equipment and to pay for tickets to events for young people and/or their personal assistant.
- Alongside this range of individually tailored approaches, Pathfinders also developed systems for delivering standard offers or payments to families in the form of grants for specific purposes, for example with holiday payments. A number of Pathfinders made significant payments available to families to cover additional expenses and personal assistant costs associated with a family holiday. Pathfinders, in this instance, had recognised the important benefits that can come from having a change of scene, but also how difficult it is for many families to enjoy a family break.

Checklist for Effective Practice

From this evaluation, we have seen evidence of a range of strategies that can promote a positive and beneficial take-up of Direct Payments. However, such evidence also suggests that the actions below will only prove successful if the local authority chooses to embrace and champion the principles that underpin Direct Payments and personalisation. Effective practice to improve short breaks will involve local authorities and their partners:

- Ensuring that Direct Payments and personalised funding are integral components in their overall strategies and plans for delivering short breaks to the diverse communities that they serve.
- Ensuring that clear and precise information is available to families about Direct Payments and personal budgets and how they can access them for short breaks. This information needs to be available in a number of formats and consider, for example, the needs of individuals where English is not a first language.
- Ensuring that clear and precise information is made available to health and social care staff so that they are able to advise and inform families and young people (and other practitioners).
- Ensuring that senior managers (and other key officers) understand, promote and support the implementation of Direct Payments and personal budgets.
- Ensuring that extensive advice, information and support is available to families to help people to make personalised funding work – such support and advice may come either from a commissioned independent agency or from a separate team within the local authority.
- Working to identify and involve parents who are willing to give ‘peer advice’ to other parents in an effort to provide informed, experienced guidance to potential new users of Direct Payments.
- Remembering that Direct Payments are not an option that is appropriate or welcomed by all families and ensuring that practitioners do not exert undue pressure on parents who wish to pursue different options.

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