

Short breaks for disabled children

Briefing Paper No. 3 – Family participation



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.

Contact Details

Centre for Disability Research

Chris Hatton
Professor of Psychology, Health and Social Care
Centre for Disability Research
Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YT
cedr@lancaster.ac.uk

National Development Team for Inclusion

Rob Greig
Chief Executive
National Development Team for Inclusion
Montreux House
18A James Street West
Bath
BA1 2BT
office@ndti.org.uk

Additional copies of these Briefings Papers can be downloaded from –

http://www.lancs.ac.uk/shm/research/projects/short_breaks/outputs/index.php

or from

<http://www.ndti.org.uk/who-were-concerned-with/children-young-people/short-breaks-for-disabled-children/>

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 (Hatton et al., 2011, Greig et al., 2010, Welch et al., 2010, Langer et al., 2010). 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 (DfE, 2011a), 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 (DfE, 2011b) 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 (DfE, 2011b).
- The green paper on special educational needs and disability (DfE, 2011c) 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 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:

1. 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.
2. 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.
3. 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.
4. Ensuring the commitment to working closely with families is reflected and acted upon throughout the organisation.
5. Involving families in all stages of the commissioning process and enabling front line staff to access individual support packages without recourse to bureaucratic processes.
6. Challenging providers to involve families in the monitoring and evaluation of their services.
7. 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.

References

- DFE 2011a. Children and Young Persons England: The Breaks for Carers of Disabled Children Regulations. <http://www.legislation.gov.uk/uksi/2011/707/made> (Accessed August 2011). London: Department for Education.
- DFE 2011b. Short Breaks for Carers of Disabled Children: Advice for Local Authorities. London: Department for Education. <http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf> (Accessed August 2011).
- DFE 2011c. Support & aspiration: A new approach to special educational needs and disability. A consultation. London: Department for Education. The Stationery Office. <http://www.official-documents.gov.uk/document/cm80/8027/8027.pdf>.
- GREIG, R., CHAPMAN, P., CLAYSON, A., GOODEY, C. & MARSLAND, D. 2010. Short Breaks Pathfinder Evaluation. Research Report DFE-RR062. <https://www.education.gov.uk/publications/standard/publicationdetail/page1/DFE-RR062> (Accessed August 2011). London: Department for Education & National Development Team for Inclusion.
- HATTON, C., COLLINS, M., WELCH, V., ROBERTSON, J., EMERSON, E., LANGER, S. & WELLS, E. 2011. The Impact of Short Breaks on Families with a Disabled Child Over Time; the second report from the quantitative study. [Publication via the DfE website expected end of November 2011].
- LANGER, S., COLLINS, M., WELCH, V., WELLS, E., HATTON, C., ROBERTSON, J. & EMERSON, E. 2010. A report on themes emerging from qualitative research into the impact of short break provision on families with disabled children. Research Report DCSF - RR221 London: Department for Children Schools and Families. <https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-RR221> (Accessed August 2011).
- WELCH, V., HATTON, C., WELLS, E., COLLINS, M., LANGER, S., ROBERTSON, J. & EMERSON, E. 2010. The Impact of Short Breaks on Families with a Disabled Child; Report One of the Quantitative Phase. Research Report DFE-RR063. London: Department for Education. <https://www.education.gov.uk/publications/RSG/AllRsgPublications/Page9/DFE-RR063> (Accessed August 2011).

The following may also be of interest

8. CeDR and NDTi, *Short breaks for disabled children; Briefing Paper 1 Commissioning*. 2011, Centre for Disability Research, Lancaster University and the National Development Team for Inclusion: Lancaster
9. CeDR and NDTi, *Short breaks for disabled children; Briefing Paper 2 The Range of Short Breaks*. 2011, Centre for Disability Research, Lancaster University and the National Development Team for Inclusion: Lancaster
10. CeDR and NDTi, *Short breaks for disabled children; Briefing Paper 3 Family Participation*. 2011, Centre for Disability Research, Lancaster University and the National Development Team for Inclusion: Lancaster
11. CeDR and NDTi, *Short breaks for disabled children; Briefing Paper 4 Personalised funding*. 2011, Centre for Disability Research, Lancaster University and the National Development Team for Inclusion: Lancaster
12. Wiseman, R., et al., *Towards a more ordinary life; A report on the progress of parent carer participation and the development of short breaks, 2008-2011. Together for Disabled Children*. 2011, Department for Education. <http://media.education.gov.uk/assets/files/pdf/t/towards%20a%20more%20ordinary%20life%20summary%20report.pdf> (Accessed August 2011): London