

Short breaks for disabled children

Briefing Paper No. 4 – Personalised Funding



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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 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 (DH, 2009).
- 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 (HM Treasury, 2010).
- The Department for Education has provided advice for local authorities concerning personalised funding for short breaks (DfE, 2011a) 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 (DfE, 2011b). 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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