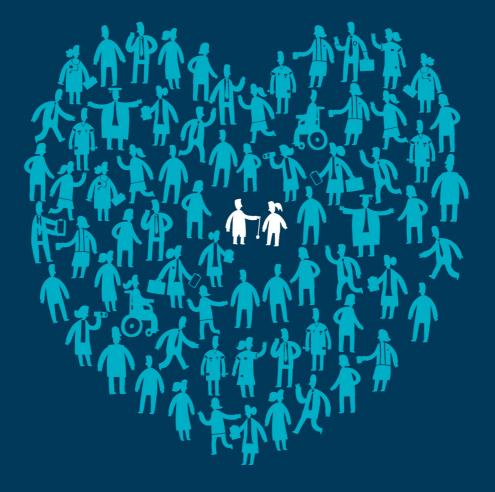
Research





What factors make for successful family-based short breaks for children with complex healthcare needs? PLR0910/057

# <u>What factors make for successful family-based short breaks for</u> <u>children with complex healthcare needs?</u>

# **Rob Fountain**

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The reports were completed between September 2009 and February 2010 and apply a wide range of research methodologies. They are not intended to be longitudinal research reports but they provide a snapshot of the views and opinions of the groups consulted as part of the studies. As these projects were time limited, the evidence base can be used to inform planning but should not be generalised across the wider population.

These reports reflect the views of the practitioners that undertook the research. The views and opinions of the authors should not be taken as representative of CWDC.

A new UK Government took office on 11 May 2010. As a result the content in this report may not reflect current Government policy.

# What factors make for successful family-based short breaks for children with complex healthcare needs?

# **Rob Fountain**

## Abstract

**Title:** What factors make for successful family-based short breaks for children with complex healthcare needs?

**Introduction:** Shared Care Network - the national short breaks charity - is interested in improving knowledge on what works in family-based short breaks for children with complex healthcare needs who are known to be 'hard to place'

**Aims:** To record parental experiences of accessing family-based care, obtain practitioners views on the key themes identified and to consider reasons for low response rate.

**Context:** The government's Aiming High for Disabled Children programme has invested heavily in short break provision. Children with complex healthcare needs are one of the priority groups to be reached.

**Methods:** Face to face interviews conducted with parents; practitioner views sought on interim findings; telephone interviews with 'gatekeepers' to explore reasons for low response rate.

**Findings:** Family-based short breaks are valued by parents. Nine key success factors for short breaks identified, including the benefits of the short break carer already knowing the child and family, ready access to required equipment and ensuring the child's social needs are met as well as the clinical ones. Evidence found over-consultation of parents and need for more creative ways of engaging these parents.

**Implications:** Family-based short breaks can be successful for children with complex needs. Direct Payments may be of interest to parents seeking this service, but this will require thought about how the placements are supported. The short break sector needs to develop its evidence base, beyond consulting with parents on perceptions.

**Conclusions:** More research should be commissioned into short break provision.

# Introduction

Short break provision for disabled children is a crucial element in the support to disabled children and their families. The Aiming High for Disabled Children programme in England has seen considerable government investment to develop short break services<sup>1</sup>. Ensuring access for children known to be 'hard to place' in short break services is a key element in the transformation programme. Children with complex healthcare needs are amongst those known to be least likely to receive a family-based short break.

This research project sets out to add to knowledge to what makes successful family-based short break provision for children with complex healthcare needs by seeking views of parents and practitioners.

Encountering an extremely low response rate, the research also considers relevant issues in involving the parents and carers of children with complex needs in primary research which may inform future attempts to develop the evidence base of short breaks.

# Aims of the project

In line with the mission of Shared Care Network, the aim of this research was to improve short break practice. The specific focus on children with complex healthcare was a response to knowledge that this group of children are currently less likely to benefit from a family-based short break.

Recognising the position of families as experts in their own lives, the chosen methodology started from the perspective of parent carers.

The aims for the project were:

- To record the experience of families of children with complex healthcare needs accessing family-based short break provision.
- To identify recurrent themes in the experience of these families.
- To compare these derived themes to the perspectives of professionals involved in the support of short break placements.

Even with targeted sampling the number of parents coming forward to contribute their experiences was very low across four local authority areas. Given this low response rate, an additional aim for the project emerged:

• To identify learning points in methodology to inform future research involving the parents of children with complex healthcare needs.

<sup>&</sup>lt;sup>1</sup> Department for Education, May 2010, http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC/

# **Context**

Short breaks for children with complex healthcare needs is a service model (short breaks) and a group of children subject to considerable attention as a result of policy developments in England.

Aiming High for Disabled Children (AHDC) is the UK government's transformation programme for services for disabled children. Of the significant funding made available by the government for developing services for disabled children, the largest investment (£269m of revenue funding for local authorities over the 2008-11 Comprehensive Spending Review period) is for the development of short break services (DCSF, 2007).

AHDC is underpinned by evidence of an inverse care law operating, whereby children with the highest level of need are the least likely to receive services (TDC, 2010). As such AHDC prioritised five groups - children over the age of 11 with moving and handling needs; children and young people where challenging behaviour is associated with other impairments (e.g. severe learning disability); disabled young people aged 14+; those with autistic spectrum disorders and children with complex healthcare needs. The last two were later identified as the main groups for new services to target.

The terminology 'children with complex healthcare needs' is contentious. Such a definition can reinforce a medical model where problems rest with an individual, rather than it being the systems and services that have to be negotiated to get these needs met that are recognised as 'complex' (Lenehan et al, 2004; Limbrick 2007). 'Complex healthcare needs' is used in this project as shorthand for:

'Children and young people who are dependent on their parent or carer carrying out an invasive clinical procedure which is essential, either as part of their routine care, or within an expected emergency situation' (Lenehan et al 2004, p24)

Within this, routine or regular care includes nasogastric and gastronomy feeding, oxygen dependency and stoma care. Expected emergency situations include the use of rectal medication to control epilepsy. Whilst the number of disabled children with these needs is increasing (DoH 2003; Heaton et al, 2003; Glendinning et al 2001) this group of children are also known to be amongst those considered 'hard to place' in relation to short break services (Prewett, 2000). Studies into support for parents caring for a 'technologically dependent' child at home identify major problems in obtaining a break from caring because of the lack of appropriate services (Kirk & Glendinning, 2004).

Some progress has been made in improving short break provision to these families. A lack of clarity over the responsibility of health professionals in training short break carers and fear of litigation should something go wrong have been addressed by government intervention and the drawing up by the Royal College of Nursing lists of permitted and prohibited tasks (Lenehan et al 2004). The emergence of contract carer services - using salaried carers to provide placements - is also linked to the increasing complexity of the needs of children seeking short break care (Carlin & Cramer, 2007).

In understanding short break carer motivations, Prewett (2000) identified the two main reasons why carers agreed to placements with children with complex healthcare needs as 'knowing the

child and their family' and a 'desire to help'. Carers also reported that prior experience of looking after a disabled child was important.

# Methodology

This research set out to start from the personal experience of parents. Face to face interviews with parents to capture individual stories were considered the most direct route to enable this. A clear ethical framework was followed, starting with an approach to the GSCC for guidance and a commitment to observe the social work Code of Practice in all interactions with service users and carers (GSCC 2002).

Three local authority areas representing a range of geographic areas were identified to conduct the research in. Authority A is a City Council; Authority B is a medium sized shire county; and Authority C a large rural county.

Approaches were made to the Heads of Children's Services in these areas to secure consent to conduct the research. Authority C responded with a formal research governance process – encompassing an application form and a telephone interview. Permission was ultimately declined on the basis of the research duplicating consultation with parents on the subject of short breaks.

In Authorities A and B the researcher was directed straight to the family-based short break or Children with Disabilities team in the area.

A fourth Authority (D) was identified as a replacement following the decision from Authority C. Consent was given after an approach to the service manager. Packs were produced for parents containing: a covering letter, a consent form, a request to participate form (giving 3 ways for parents to express a willingness to contribute) and a freepost envelope. Participants were offered a £20 voucher for participating. Packs were supplied to the relevant social care team in the three Authorities (A, B and D) who were 'gatekeepers' in distributing the invitations to parents.

Gatekeepers were given sight of what was in the packs and instructed to distribute them to parents/carers of children with complex healthcare needs either receiving or on a waiting list for a family-based short break. It was agreed that packs could either be posted or hand-delivered. Parents agreeing to participate responded direct to the researcher and face-to-face interviews arranged. In one case a telephone interview was conducted. Signed consent was obtained prior to each interview.

Broad, open-ended questions were used, with the researcher probing for more detail where appropriate. All interviews were tape-recorded with consent. Recordings were not fully transcribed, but used to supplement field notes.

Where interviewees described similar experiences or views, these were grouped together and presented as a number of key factors for successful short breaks and summarised in a brief report (two pages). This report was circulated to a number of practitioners to obtain comments on whether the key factors identified were typical of successful short break placements.

Responses were received from family based team managers (n=3 from both statutory and voluntary sector providers); a service development manager, a family link social worker; and

two paediatric nurses. With a low response rate from parents (n=3) an informal telephone interview (following a semi-structured interview schedule) was sought with the gatekeepers in each authority (A-D) to elicit their views on why the response rate may have been so low. Telephone interviews were completed with 2 of the four areas.

# <u>Findings</u>

Of the three parent respondents:

- two were long term foster carers who accessed short breaks as part of their on-going support package (NB: the term parent is used in this report as short hand for parent / carer);
- all had experienced positive family-based short breaks and were clear that they and their children valued this provision;
- one parent reported having had one successful and one unsuccessful placement for their child;
- one parent had previously accessed family-based short breaks for another disabled child without additional healthcare needs and was able to compare this with their experience of a placement for a young boy with complex healthcare needs;
- one parent had experienced a successful long-term placement, but this had recently encountered problems;
- all three children whose short breaks were discussed were boys.

Nine key factors emerged from the parental interviews as having a positive impact on familybased short breaks. These were in the main supported by the professional group who responded to the two page summary of findings.

# 1. The short break carer already knows the child

"The key is that she knew him. She had an understanding of what his needs were going to be." (Parent)

Getting to know a child's needs takes time and some personal connection to the child. People who already know a child – either from a professional role such as a link to the child though school; or a connection through the family's network - are seen to be well placed to provide a short break if they express an interest in doing this.

One professional questioned this factor, stating that an existing informal relationship could make it difficult to initiate boundaries, especially around care tasks that are inappropriate or not permitted.

# 2. The short break carer has previous experience of children with complex healthcare needs

If the carer does not know the specific child prior to a short break placement, previous carer experience of working with children with complex healthcare needs can make a difference. One parent said she would not agree to a placement where the proposed carers did not have some previous experience of children with complex healthcare needs.

Carers with prior experience have awareness of what is required in supporting children with complex needs and may have prior training and knowledge of associated care / clinical functions.

"Previous experience helps. It is really tricky explaining what their work will entail if they have no prior knowledge. Training a carer for a second child with a tracheostomy takes a fraction of the time compared to the first" (consultant paediatric nurse).

Training carers on the child's individual care and medication procedures was reportedly done largely by cascade from parents, but practitioners noted that carers should receive child-specific training from health professionals "in addition to the valuable knowledge shared by the parents" (short break team manager).

Prior experience of specific healthcare needs should not automatically mean a carer is matched to a child with these needs if other factors are not in place. A single carer with relevant clinical experience, might not be safe to respond to a medical emergency if on their own with the child.

#### 3. The short break placement starts when the child is young

It may be easier for an effective short break connection to be formed between child, parent and short break carer when the child is younger. As the child's needs change as they get older these may be better accommodated when the placement is already established. Engaging short break carers for the first time when he child is older can be more complicated.

"If you get someone involved while the child is small and sweet and cute and they build up a personal link to the child – just like you have – you can build on that." (Parent)

Linked to this, practitioners noted examples of children developing healthcare needs once a placement is well-established and in these cases carers may agree to undertake training to be able to continue the link.

Practitioners did stress that placing older children was done regularly.

#### 4. Any equipment required is available for short break carers in good time

"He's a tall lad, three foot 9 – not heavy, but he has no control over his body so if you're trying to lift him or trying to bath him or trying to carry him upstairs without the right equipment it's just dangerous." (Parent)

Where children require equipment to assist in providing safe care this should be provided as soon as the need is identified. Anticipating the need for equipment in the short break placement can mitigate against delays in arranging provision.

Social care and health practitioners supported this strongly as a key requisite. Equipment review and advice from an Occupational Therapist, ideally one who knows the specific child, was cited as important. A paediatric nurse highlighted how this can be problematic if a short break carer provides multiple placements as there may be a need for a number of OTs to liaise and potentially provide separate equipment for each child.

## 5. There is plenty of time allowed to build up to the short break

Short break placements require parents to trust the carer to be able to meet their child's needs. Time must be allowed for visits in both the child's home and the carer's home for the relationship to develop, and for techniques to be taught and observed.

"It's just very little steps to build up that confidence." (Parent) "Our ethos is that the matching process is done at the pace of the child and family, whether they want the placement to start as soon as possible or want a slow build up over 6 months..." (Paediatric nurse)

#### 6. There are good handovers before and after short breaks

Linked to the need for more time when the child has complex healthcare needs compared to placements with other disabled children, there may also be a need for more face to face contact between parent and short break carer which needs to be allowed for. Handovers may be more involved with information to be shared on feeding, medication, and health, either for parents to explain new routines or for carers to feedback on how the child has been during the placement.

"Needs to be more face to face contact, more shared care at the beginning and maybe if there's any changes, handovers are a lot.... take longer. Probably the biggest difference is more contact." (Parent)

In the absence of face-to-face handovers, communication diaries moving between home, school and short break placement are important for passing on relevant details.

# 7. Relevant information on the child is shared between all parties

A Health Care Plan is essential for each child requiring invasive procedures (Lenehan et al 2004). Parents confirmed that a clear and detailed care plan served as the core resource in ensuring the child's needs are consistently met on the short break.

The existence of a number of professionals with involvement in different aspects of the short break (child's social worker, family link worker, foster carer support worker in cases where permanent foster carers receive short break care) requires excellent lines of communication to exist to ensure relevant information flows efficiently between parties and not into gaps in between different roles.

A moving and handling plan, which is regularly updated, was also identified as crucial (social worker).

#### 8. Carers are confident in their role

Parents need carers who are competent and confident in carrying out key care tasks – e.g. tube feeding – without the need to call upon parents for guidance during the break. One parent who had experienced a placement breakdown described the impact when trust was lost:

"Our respite is not that important that we would continue if we have a weekend off and we spend all our time thinking is he okay, is he warm enough, has he had the right medication, has he had the right hygiene needs."

Confidence is also demonstrated when carers are able to say when they do not feel able to perform a certain task.

One short break team manager identified the importance of carers having (with the parent's consent) the ability to contact health professionals for advice when the child is with them on placement as preferable to the carer having to disturb the parents.

Carers should also be clear about what to do in case of emergency (e.g. a feeding tube becoming dislodged). Again a thorough Health Care Plan is the place to confirm what carers should do in such situations.

**9.** Short break carers meet the social needs of the child (as well as clinical needs) Disabled children are more than their clinical and personal care needs and just like other children want to have fun and enjoyment in the short break. Successful placements are ones where short break carers are able to support the social needs of children and offer them enjoyable and stimulating opportunities.

"(Short break carer) was brilliant with him and used to do things with him that we would never have got round to. She used to take him on boat rides, steam train rides all kinds of nice things... he used to do some great things with her. It was really wonderful for everybody" (parent)

#### Findings:

Research findings can often take precedence over issues concerning methodology (Sanghera & Thapar-Bjorkert 2008). Reflecting on the research experience as well as the findings from the interviews conducted, some relevant learning on methodology came from the follow-up telephone interviews with the gatekeepers.

#### **Over-consultation**

A clear message came back that parents are consulted a lot – especially under the AHDC programme. One practitioner fed back that whilst she saw the value of the research, she felt some dread at the thought of sending out another request for information to parents and was anxious about whether anyone would respond. Similarly, the decision of Authority C to decline consent to the research taking place was on the grounds of a desire to 'avoid our service areas being over-researched' (E-mail from representative of Authority C).

#### Time is precious

Whilst the offer of £20 in vouchers was seen as a recognition of the parents' contribution, it is time that is seen to be most valuable to parents of children with complex healthcare needs.

"The routines that the parents of these children have – I think they need time more than money. It's about whether they have the mental energy to take part in an interview" (senior practitioner).

#### Support needs of parents

It was recognised that some of the parents receiving the research pack may have needed support to consider whether they wanted to participate. Literacy was assumed by the approach taken, but may have been a barrier in some cases.

"Those families it would have gone to, some would have needed support to talk them through it and to understand the value of it." (Service manager, Authority D)

#### Implications for practice

It is inappropriate to draw too firm a set of implications from the study given the low response rate, although the supporting comments from practitioners allow some implications in support of good practice to be proposed.

The parents interviewed were clear that family-based care was a valued provision and one they all knew could be successfully arranged for children with complex healthcare needs. The factors for successful placements identified are not particularly surprising and they reinforce the guidance available in practical handbooks such as The Dignity of Risk. Health and social care need to work together to build trust with parents that those providing short breaks will be trained, equipped and confident in meeting the clinical needs of the child.

#### **Direct payments**

All the parents identified a preference for short break care provided by people who knew their child already. An implication is that direct payments and individualised budgets could support this, which will impact on the delivery of short break care.

Two parents spoke about valuing flexibility, the ability to identify their own carer and finding the input of statutory bodies frustrating. They did not directly discuss direct payments as an option. One parent, however, has now asked the local authority to provide direct payments for her.

Existing family link arrangements have broken down because:

"the bureaucracy is staggering" and "the reason we want direct payments is so we can continue to have (carer) involved, but that we can pay her properly."

Direct payments may present a route to arranging short breaks where parents know someone who would like to offer breaks to their children.

Some of the important factors identified in this report may be easier to fulfil if a placement is funded by direct payments; others – such as accessing the right equipment and training - may, though, pose challenges. Local authorities need to consider how they can support parents wishing to use direct payments to gain flexibility, whilst ensuring that children with complex healthcare needs are safe when staying away from the family home.

#### Future research

It is precisely because parents of disabled children, and the children themselves, find it hard to have time out during their regular daily routines that short break provision is so crucial. On reflection, a research methodology requiring parents to spend up to an hour talking about their

experiences seems destined to have a low take-up. The implication is for researchers to be considerate to the daily existence of parents when seeking to consult them.

#### Amount of consultation

Researchers need to be aware of other consultations that parents are asked to undertake and factor this into the methodology they employ and the timing of research projects.

It is also relevant, though, that service providers should be alert to over-consulting parents on 'what they want'. If parents' ability to contribute personal experience is exhausted by responding to requests from service providers on what they would like, we may lose the opportunity to engage parents in independent research that may better inform the evidence base for short break services as a whole.

#### Ways of obtaining parental views

The high value of time for parents of children with complex healthcare needs indicates that more creative ways of accessing parents' views may be advisable. One practitioner outlined an approach where a social activity, accessible to parents, their disabled child and any siblings is organised to provide an environment which itself serves as a mini-short break and may be more conducive to parents being able to contribute views on the area of interest to the researcher.

#### Introducing research opportunities to parents

Parent respondents in this research were all white British and from professional or social care backgrounds. These groups are more likely to participate in health services research (Tadic et al, 2009) which may have implications for the basis on which services are planned (Benedict, 2006).

Services already involved in supporting families could play a role in presenting research requests face-to-face to parents. This may allow for the research to be explained to the parent in a way that conveys the purpose more easily than a letter and allow access to research to those less confident in reading and responding to written invitations.

Whilst over-burdening gatekeepers who are busy frontline workers is a concern, such an approach may also ensure that research findings are more accessible to practitioners than when the methodology seeks to by-pass them. As one service manager said:

"The pay-off for us is that we get the answers to how to better serve these parents, so we would want to be involved. We would just need time and enough notice to do this well." (Service Manager, Authority D)

#### **Beyond parent consultation**

Small scale, qualitative studies such as those used in this study and by every local authority consulting parents under AHDC are valuable, but not sufficient (Axford et al 2009). Much of the 'good practice' guidance that has emerged in support of AHDC tends toward descriptors of 'innovative' local provision, rather than formal research into what works (see for example SCIE 2008).

As the short break sector emerges out of the AHDC transformation, it will be important that an evidence-base also develops. Some excellent practice guides already exist (Carlin et al 2004) and there is some evidence of the impact of short breaks for children with autism (Tarleton &

Macauley 2002). A similar study into whether and how short breaks benefit children with complex health care needs is needed.

Existing research in related fields should also be considered for relevant learning for short breaks. Evidence into kinship foster care, for example, has explored the benefits of kinship placements as against placements outside existing networks (Winokur et al, 2009); of privately arranged versus publicly-arranged placements (Hunt, 2003); and the need for proportionality in assessment processes when supporting a kinship placement (Argent, 2009). The implication is the need for robust evidence into short break provision to ensure that services are shaped on what works as well as what parents say they want.

# **Conclusion**

Family-based short break provision is an important service for families with children with complex healthcare needs. This research project has helped clarify some of the useful things that are known at a 'parental experience' and practitioner level about the factors that can lead to placements of this type being successful.

The methodology employed - albeit well-intentioned – proved flawed and the researcher has benefitted greatly from the opportunity to reflect upon how asking parents views and what they want is not sufficient.

Children with invasive healthcare needs require a complex arrangement of services to work together to enable them to enjoy stimulating and safe short breaks. Direct payments may come to represent a useful route to funding family-based placements where parents identify someone who knows the child to provide this support. To do this safely, though, will require short break providers to be creative in how they support this. More evidence of 'what works' is needed within the short break sector to inform the implementation of an ever-changing array of short break provision.

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