

# Critical features of short break and community support services to families and disabled young people whose behaviour is severely challenging

Journal of Intellectual Disabilities  
15(4) 252–268  
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sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/1744629511433257  
jid.sagepub.com  


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## Abstract

Parenting a child with severely challenging behaviours is very stressful and threatens family well-being. Short break (respite) services are commonly provided as a support to families but surprisingly little attention has been paid to adapting these services when children and families have complex needs. This article describes the model of service that has evolved in three separate locations which successfully provides overnight short breaks and/or community-based support to families. The model was documented and validated through individual and group interviews with a range of stakeholders – around 30 in all. The services are embedded within multi-agency partnerships and four particular features are highlighted: the values and ethos underpinning the service; the service procedures; the organization of short breaks; and the role of an intensive support/outreach service. The rationale for complex service models is discussed and the key lessons for replicating this model are reviewed.

## Keywords

challenging behaviour, family support, respite, short breaks

Date accepted: 23/11/11.

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## Background

Children with learning disabilities and severely challenging behaviour place particular strains on their families, with maternal ill health, depression and family breakdown often resulting (Hastings, 2002). In extreme cases the child may have to move to high-cost residential placements (McGill *et al.*, 2006). A more cost-effective approach is the provision of family support services. In the main these have taken the form of 'respite' – short break – provision, and the UK government has recognized the need to extend these services (HM Government, 2007). Ironically children with additional needs due to autism or challenging behaviours may not be able to avail of these services as they are not equipped to manage their needs (Chadwick *et al.*, 2002).

However, the value of these services to parents is unclear. Certainly parental advocacy has been very supportive of such services for the break from caring tasks they provide to families (Mencap, 2010), but the empirical evidence for their longer term impact on carers is ambivalent (Robertson *et al.*, 2010). In part this may be because insufficient attention has been paid to the nature of the service that is provided to families. It is disingenuous to assume that because services have the same name they deliver the same type of provision. It is surprising to note the dearth of empirical research into the style and nature of provision that is best suited to the needs of families, despite residential short break services being among the longest established and more expensive forms of support to families (Mooney *et al.*, 2008), and the even greater lack of research into the adaptations required to meet the needs of children with more challenging needs.

One approach would be to examine the characteristics of a 'good' service as acknowledged by commissioners, such as social workers, and by parents. Both groups will have had experience of other services against which their comparisons can be made. In addition the range of stakeholders who have direct experience of the service would be invited to identify in their own words what makes the service 'good'. From these responses it should be possible to build up a model of the attributes required of effective short break services. Moreover the validity of this model should be tested across services in different localities to ascertain its generalizability. The resulting model would yield a set of quality indicators that can be used by providers and commissioners to review existing provision and formulate improvement plans. It would also contribute to assessments of cost-effectiveness.

In sum then, the aim of this study was to use a multi-informant approach to document the essential features of a successful short break and community support service by Action for Children in three locations in the UK to families whose children have behaviours that severely challenge. The latter was based on Emerson's (2001) definition:

Severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

The review of the service model would be based on program theory as a means of identifying the processes that underpin its functioning (Rossi *et al.*, 2004). Although the managers and frontline staff delivering the service were the main informants, the views and experiences of parents using the services were also sought as well as those of health and social services staff who referred children to the services. A subsequent study elaborated on their perceptions of the services (McConkey *et al.*, 2011).

## **Description of the services**

Action for Children provides in three UK cities – Glasgow, Edinburgh and Cardiff – intensive support services to families whose children (up to 19 years of age) have developmental disabilities and severely challenging behaviours that risk their exclusion from school, home or community. It provides mostly overnight breaks in a small residential home for two to seven days at a time. A complementary service is also provided in which staff will come to the family home and accompany the young person to activities within the local community while also providing advice and training to the family in managing behaviours. The services are viewed as specialist provision and are available only to selected families within defined geographical areas. There is an expectation that children and families will move on as their needs change and certainly once the young people become adults. In total 123 families had accessed the services in the period 2008–2010. Some children received both forms of support ( $N = 37$ ) but more usually it was either residential short breaks only ( $N = 63$ ) or community support only ( $N = 23$ ). Details of the family and child characteristics were obtained from service records and fuller information is available on request.

### *Family characteristics*

The families predominantly have low incomes (65%) and a high proportion were lone parents (40%). They lived mainly in rented accommodation (60%) and were dependent on welfare support benefits (55%), perhaps as a consequence of full-time caring. Many of the family carers had poor health (53%). With nearly half of the families there is some risk of family break-up, and two in five children are at risk of having to move out of the family home. When there was a risk of family breakdown, a combination of short breaks and community support tended to be provided.

### *Child characteristics*

Overall more boys (74%) than girls used the services, especially the combination of short breaks and intensive support. The children were mostly teenagers, although they accessed community support at a younger age than they did the short break services. Nearly all attended special schools (90%). Upwards of two-thirds had an associated diagnosis of autism. Around one-quarter of the children were dependent on others for feeding, dressing and toileting. Over 70% of the children had one or more behaviour problems rated as severe or moderate, of which sleep problems were the most frequent. Children receiving both residential short breaks and community support tended to have more behaviour problems and to be on medication for them.

### *Staffing*

In May 2010, 64 staff were in post across the three services: eight (13%) held some form of managerial or senior post, 47 (72%) were project support staff, four (6%) were in administrative or housekeeping roles, and five (8%) were employed as casual staff. Around 70% of the project staff held part-time or casual contracts and worked a median of 9 hours per week (range 2 to 37 hours). All but four managerial and project staff held some form of qualifications including nursing, social work, N/SVQ Level III and HNC in social care.

## **The process for documenting the service model**

Four sources of information were cumulatively used to document the service model.

First, documentary materials that described the services were analysed. This included publicity and information leaflets, papers describing the services, self-assessments provided as part of external inspections, and recent reports from external inspections.

Second, the three service managers in each location were interviewed about the form and functioning of their local service, and notably how it has evolved in recent years. In addition two senior staff gave more detailed information about the community support offered in the community and family homes. These five interviews (over 6 hours duration) were audio-recorded and transcribed verbatim, and thematic content analysis was used to determine key features of the model.

Third, a range of stakeholders from each location was invited by the service manager to attend a consultation meeting about the services. These included mothers and fathers, front-line staff, service managers and deputies, clinicians, social workers, and health and social service managers. Around 30 persons participated in all. A focus group methodology was used with the first author as facilitator, using the service model emerging from the documents and staff interviews as the focus for discussion. These groups provided an internal validity check of the model, as all participants in the consultation had direct experience of the services and were actively engaged with the daily operations. The three separate focus group consultations also provided an external validity check. The discussions, which lasted around 80 minutes in each location, were audio-recorded and transcribed verbatim, and again thematic content analysis was used to confirm the main domains within the model and the key features of each.

Fourth, a draft report on the service model was circulated to all participants for comment, and this was discussed and revised at a subsequent meeting with them. In addition senior staff in the organization who had not been involved in the process commented on the model.

## **The service model**

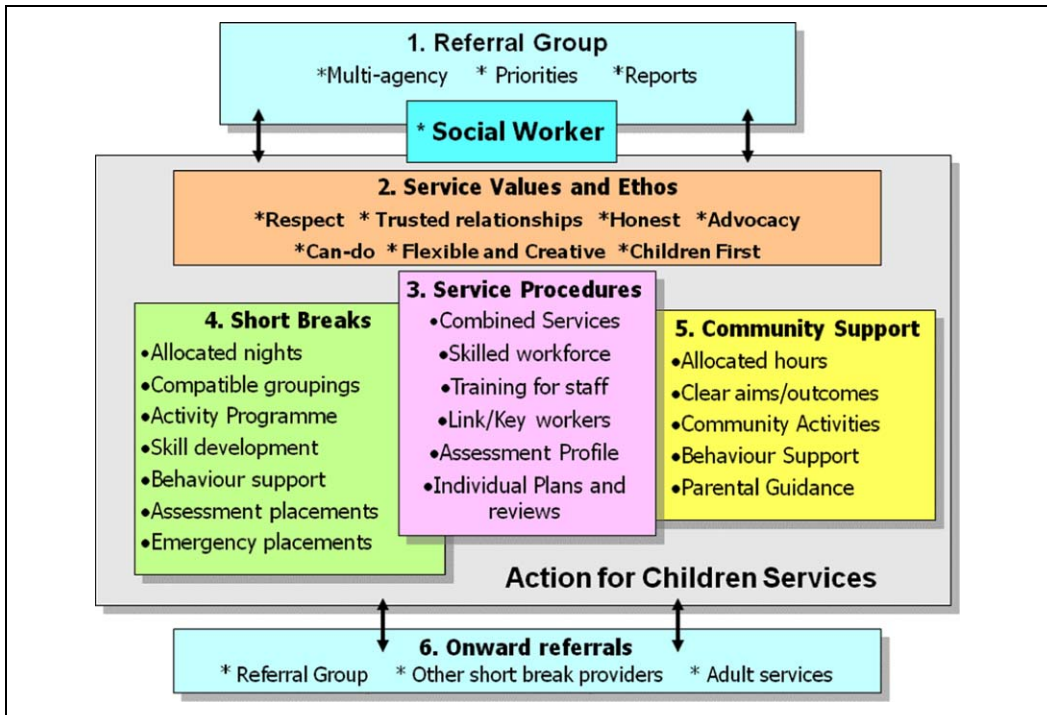
Before going into the detail of the service model, it is important to acknowledge the overall context in which the services operate. Participants identified two facets: (1) the organizational context provided by Action for Children; and (2) the partnerships with other services in the localities in which they operate.

Action for Children is a major UK provider of services to disadvantaged children and families. It operates 74 specialist services supporting 6000 disabled children; a further 9000 disabled children access universal family support, youth, fostering and adoption support. The organization has common policies and procedures and arranges regional meetings for service managers as well as regular induction, in-service and refresher training for staff, particularly accredited training in behaviour support.

In addition, the three services in this study are linked to the wider service networks of learning disability (LD) teams and child and adolescent mental health service (CAMHS) teams; to special and mainstream schools; and to other family support services in their area, notably home support (domiciliary services), befriending schemes and other short break providers. These linkages have been built up over 10 and more years since the commencement of the services in the late 1990s.

## **Key features of the short break and intensive support service model**

The six key features of the service model to emerge from this consultation process are summarized in Figure 1. Each element within the model is explained in turn. As far as possible, the model is



**Figure 1.** The model for short breaks and community support provided by Action for Children

described using the words of the different stakeholders from across the three service settings. (Note: the term ‘manager’ refers to Action for Children staff who are in a management role.)

### Referral group

Families are referred to the services by a group of personnel drawn from the statutory services whose remit is to commission services for families with assessed needs in that locality. Although the names, form and function of these groups vary across the three locations, their contribution to the service model is common in four important respects, as follows.

*Multi-agency.* The groups have representatives at a minimum from health, social services and education, all of whom can nominate children and families for consideration by the group. Voluntary sector representatives might also be included. Their remit covers a range of children’s services and they provide a coordinating function across agencies and disciplines. They are a tangible expression of partnership working across agencies and sectors which facilitates joint commissioning, although health tends to be the dominant referral agency with social services managing the ‘gatekeeping’ function. More crucially these groups enable individual services such as Action for Children to access support and cooperation from the other agencies involved with the children and families, and for them to reciprocate in their support of others. These respectful relationships have developed over time.

I always felt that there was a big link between school and here (Action for Children), in so far as the school could ask here for help and advice as to what we were doing, so it was coordinated . . . And the keyworkers would come into school and see what X was doing in school. They're very open, but that's the sort of school he's in. (parent)

**Priorities.** The group decides the children and families that should be referred to the service. Usually the family social worker will outline the needs that have been identified from assessments undertaken and makes the case for why a referral should be made. Family issues are often a trigger. However the group also takes account of the existing pressures on the service and may hold off referring a family until a place becomes available or negotiates with the service about freeing up a place, although this may mean an existing family being referred elsewhere or having their services reduced. In a sense the group manages the waiting list for the service.

**Reports on children and families.** The families and children are well known to services and a wide range of assessments have been undertaken with them. Reports can be forwarded to the services, although it was noted that the quality of information that is passed on about children and families can be variable. However if the keyworkers and managers in the services identify any gaps in information, they can contact the relevant personnel in health, education and social services as they are all part of the process.

A holistic approach is key and that we speak to all providers, 'cause every time we speak to somebody, we find something new out. We know that the children we are working with are very different in different settings. (manager)

**Social workers.** A vital point of contact between the referring group and the service is the social worker allocated to the families. In particular they establish clear expectations with families of what services will be provided. The services prefer that this is done jointly with their staff and the social worker visiting the family at home. The social worker is also an ongoing link in reviewing and adjusting needs for services.

We just need to make sure from the outset that what we understand from the local authority is the same as what the parent understands, because understandably when people are stressed and frazzled they hear some things and they don't hear other things, and sometimes that causes problems further down the line. (support staff)

### *Service values and ethos*

The interviews identified the values and ethos that the services strived to embody in their work. These could be grouped into two strands: a first strand which described the nature of the relationship the service has with families, and a second strand that relates more to the ethos or culture of the services.

#### *(a) The relationship with parents*

**Respect for parents.** The service needed to have a real empathy for parents and appreciate the stresses they experienced.

To me it's not flying in as experts – we can do this, and you as families need to get as skilled as we are at doing this – [rather] it's about going and saying: 'You can do this, these skills are there and have always been there.' (intensive support staff)

**Trusted relationships.** The importance of trust and building strong relationships between staff and services was emphasized.

Looking back over the years I have laughed and giggled with staff and I have also sat and sobbed my heart out with staff and that is not something I have done with school or anywhere else. You do definitely build up a relationship with them. (parent)

**Honesty.** This was another crucial hallmark of the service in a number of senses. Staff need to be honest when things are not going well but also have the confidence to challenge parents when change is needed.

I think staff have to be understanding but also honest and willing to be assertive and challenging because you can't always just agree with parents all the time, because you're not really helping them then by doing that. (manager)

**Advocacy.** Staff also were seen as important advocates for families, speaking up for them when they are persuading others of their needs.

If you are going with somebody who is professional and they are saying the same as you, people do listen. Otherwise they think that you are slightly exaggerating. (parent)

Crucially, these relationship values, such as respect, honesty and trust, are equally applicable to staff relationships within the services.

I think workers have got to feel safe, to feel open, and they've got to feel the work environment is where they can feel supported rather than blamed, or to know if there are difficulties that we will work through them as a team. (manager)

In keeping with the ethos, the services hold regular consultations with parents either individually or as part of a steering group for the service.

### **(b) Service culture**

The discussions also identified a further set of values which relate to the culture that has been nurtured within the service.

**'Can-do' attitude.** The service strives very hard *not* to say no. This is evident in accepting some challenging referrals as well as in sticking with others through difficult times.

We worked really intensely with a particular young man, as did other services, and the level of violence was really quite extreme. We have a non-exclusion policy, so although we dropped off the respite service 'cause he wasn't coping with coming into the house, we kept the outreach service on and we continued to do that. (manager)

*Flexible and creative.* Given the variety of challenges presented by the young people and their families, it is essential that the service is willing to be flexible and creative in its responses.

They would work outside of the box and look at how best to serve the child and the family rather than it being restrained. It's always about problem solving and how to make it work. (parent)

*Children first.* Despite the children's disabilities and behaviours, it is crucial that they are seen as children first and that staff show empathy with their difficulties and the reasons for their behaviours. This requires an understanding that not all people bring to their work.

Staff have to be very nurturing and I think very child-focused and very aware of learning the theory behind children's disabilities. It's not a question of [children] should know better, it's actually getting underneath and understanding their behaviours. (manager)

As far as possible children and young people are involved in decisions about the services and supports they are given, notably around choices of activities. This often means using non-verbal communication systems, and this has been identified as a training need for staff.

The stakeholders had little doubt that the ethos and values of the service are a necessary response to the needs of the young people and families. The services have had to nurture these values and ethos in order to be successful. As one mother said:

Because our children are very challenging, you've got to have respect and honesty and be family-centred. It's got to be, because we are all quite vulnerable; parents at times are at their lowest points so you have got to be that way. (parent)

### *Service procedures*

This part of the model relates to what the service does to meet their aims: the activities they undertake, the procedures they use and the processes they follow.

*Combined services.* One of the unique features of these services is the combination of having short breaks and intensive, home-based support within the one service. This was strongly endorsed, especially by those with responsibility for commissioning services.

Simply providing respite just takes the problem away for 48 hours, it doesn't actually solve the problem. What we needed to be doing was giving families a break but also looking at the issues of what was triggering the behaviours and looking at ways to resolve that. I think that intensive support, that has been the most valuable service as far as I am concerned. (social services manager)

*Skilled workforce.* The calibre of the staff was emphasized by various people, particularly their skills in assessing and managing behaviours.

I couldn't do my job here in the way that I do it, if I wasn't dealing with staff who are not only well trained by the organization but have a particular set of abilities from the off. In other services, where staff are maybe less qualified, I am having to go back to brass tacks with them and I don't need to do that in this place. (psychologist)

The training and support available to staff were also critical factors. Particular emphasis has been placed on training the staff in behaviour management.

All staff are trained in behavioural management, so they have trained in theory about why a child displays challenging behaviour and then the primary interventions and the secondary (ones) and then finally the last resort is physical, so they can physically restrain children if they need to, if they were a danger to themselves. They also get training in autism, in PECS and in TEACCH. (manager)

The organization's salary scales try to reflect the professionalism they expect from their workforce.

We pay better than a lot of other voluntary organizations actually, and I think that we get so much more out of the staff. (manager)

*Link/key workers.* Each family is allocated a link or key worker, especially when they first come to the service. They gather information about the family and help introduce them to the service. Matching the staff to the family can be an important consideration. It can be a demanding role and one for which staff are not necessarily prepared.

We look at the skill base the staff have, and if we think it's going to be quite a challenging family we kinda look at who in the staff team would complement that family. [Parents] like the relationship they get with that person, so it is just about who you think will get on best with them. (manager)

*Detailed assessment profile.* The individuality of each child, young person and family has to be reflected in the detailed information that is gathered prior to them joining the service, during their induction to the service and throughout the time the family is with the service. The links with other agencies are vital in building a complete picture.

Assessment reports are required by the multi-agency referral panel from each specialist area involved with the family, such as medical and social work. These detail how the child's needs and behaviours are impacting on the family. Specific clinical psychology assessments of behaviour and developmental functioning may occur prior to the young person's admission, or once a child begins to use the service. Health assessments such as blood tests or other investigations may also be carried out if the presenting behaviour is thought to relate to pain or underlying health issues.

Once the staff have signed and read all the file information and observed the child – it could be in a school setting or at another agency – then we would look to start working with the child. (manager)

All staff are required to be familiar with the content of each child's file and to add to it through their record-keeping of direct observation of the child's behaviour (in the family home, in school or at the short break service) and through an analysis of ABC (antecedents–behaviour–consequences) recording relating to incidents of challenging behaviour. The keyworker and clinical psychologist work together to develop a range of hypotheses for managing the behaviours. These plans are further tested by functional analysis: hence assessment is an ongoing process (Emerson, 2001).

*Individual plans and reviews.* The services draw up a detailed plan of aims and activities for each individual family. Also personalized behaviour support plans are developed which take account of a range of key components such as communication support plans; structured visual timetables;

environment management to reduce triggers; and strategies to be used if a child shows distress or engages in challenging behaviour.

Proactive, positive interventions are embedded in the culture and practice of the services (La Vigna and Willis, 2005). Also staff are trained on a child-by-child basis in early intervention approaches with bespoke restrictive physical interventions being used as a last resort. There is no uniform set of procedures as they vary according to local team practices; however, a robust behaviour support policy and standards underpin a degree of consistency through a set of established principles.

All staff involved with each child and family are required to follow the plan so that there is consistency in the way behaviours are managed. The plans are underpinned by risk assessments.

You will go out [to the family] and ask, ‘What is it you want, what outcomes do you want us to work to?’ This gives us the service plan that will dictate what we will do with the family. Families have to sign it and then it gets reviewed every six months, although in more complex cases we try to review it possibly every 8 weeks or 12 weeks. (manager)

Formal reviews are held at least every 6 months and are shared with other agencies involved with the children and families.

Everyone came round to our house and we sat around the table and everyone chipped in really, there was enough formality to guide the meeting and keep us on track really. You could say what you wanted, ‘cause you were in your own house. (parent)

### *Short breaks*

The services have homelike accommodation in which four or five children stay overnight in their own bedroom and share domestic-style living and dining facilities. However, the buildings have been adapted in terms of bathrooms and security features. All have generous garden and outdoor play areas. The aim is to make the stay attractive for the child.

Although the short break was to provide us with a break, but after a very short period of time I realized it was providing my son with a break as well, but because they are doing the behavioural support and everything. He is happy there and that actually increases the worth of the respite because I am happy that he is happy there. You know that is vital, it’s not just getting rid of him. (parent)

Equally the breaks can benefit the whole family – that is, including fathers and siblings.

I think that [the break] has had an impact on the siblings, both in terms of respite – because then they have time to spend with the other children. For instance, some of the families say the child can have a party on the day the child has respite or I have more time to take them to the cinema or whatever. (manager)

*Allocated nights.* Each family is allocated a total number of nights per annum as judged by the referring group. Typically this will be for two or three nights per month, although some may receive a fortnightly placement because of a greater need. Close liaison is needed with the referring group to match supply with demand.

We have a system of working out the total number of nights and hours. We give them their total and, as the children come in, we project over the year the number of hours or nights and we take it off the total

so they have a running total of what they have got left, so they know exactly the hours they have left to allocate. (manager)

With increasing demand for limited services, the temptation is to give families fewer nights, but this risks negating the benefits to them.

It's important that we provide a service that's actually worthwhile having that service, you know it's regular enough and intensive enough to make it worthwhile, rather than diluting the services to the extent where I would question whether it's worth having at all. (social services manager)

*Compatible groupings.* The short break homes try to have compatible groupings of children and young people coming to stay at the same time. This requires some very detailed planning well in advance to also accommodate parental preferences for dates and organizing staff rotas. Allocations are usually made six to 12 months in advance.

We have 45 kids and you are trying to programme all their packages, trying to look at who you just cannot have in [with others] because of their sleep patterns, so it is looking at compatibility. Some of our young people have actually asked if they can be in with other young people and we will try and do that because I think it's a social opportunity. (manager)

The short breaks have a role too in helping the young people to socialize and develop friendships.

By coming in here, they are getting used to working alongside other kids, sharing, taking turns and all those things that we need to do in society. Also increasing levels of tolerance of other people's idiosyncrasies and opportunities to make longer term friendships, which have happened here in the past. I think that social bit is really important. (manager)

*Activity programme.* The goal is to make the children's stay enjoyable through providing activities and outings. This helps them to relax and makes their behaviours more manageable.

We probably only have these children for two nights a month, so it's a break for them. We want to have something that that child enjoys, maybe there is a movie to go to, some like ten pin bowling; they would be taken to swimming quite a lot as well. (manager)

The provision of transport is vital for the young people to become involved in community activities. Each service has access to a vehicle.

We got a people carrier last year and that's been great. Especially because it's that much bigger – it's a seven seater – and the behaviours staff were experiencing [in cars] don't happen – they were getting hit a lot because they were in close proximity 'cause of personal space. (manager)

*Skill development.* Short breaks can provide opportunities for the children and young people to acquire new skills and do things for themselves.

The respite and the short break stays are often the place where you can help develop skills. It might be around a sleep programme or a toilet programme [that] has been really difficult to do at home and [staff] take that out into the home, which is an invaluable part of the service. (support staff)

The young people are encouraged to contribute to the household routines.

We just encourage them to do their washing and again preparing meals, 'cause this is something that they need to do. With one of the older boys because his family is quite chaotic, there wouldn't have been that opportunity for him to learn food shopping. (manager)

This means the breaks benefit parents in other ways.

Obviously I have learned from the staff what they were doing and I took it home and extended it, so now he does sleep, he goes to sleep now. I still have to sit outside his room until he falls asleep but it's not like I'm camping on his floor, so he's just now sleeping which is good. (parent)

**Behaviour support.** Staff also have to become adept at managing the children's behaviour. This means adjusting the environment as well as having detailed behaviour support plans that staff consistently follow.

We have to control the environment quite carefully. In the bathroom for instance everything needs to be removed as he might eat the soap and drink it out of the dispenser and pull at the toilet rolls, so it's trying to minimize any stimulation. (manager)

It can be easier to start behavioural programmes while the child is staying at the short break house, especially as the behaviour often gets worse before it gets better.

My son has an obsession of what clothes he wears, so when I buy him new joggers I don't even attempt to have him put them on at home. I send them into respite and they either come back worn or they don't, and quite often he comes back and I'm thinking – oh good they've got him into those. I can remember ringing up on many occasions and saying: how did you do it? (parent)

With certain children, two-to-one staffing is required at all times. In these instances the services count that placement as two beds, which avoids bringing in additional staffing.

If a child who needs a two-to-one is coming in, we plan to have less numbers of children in, and for some reason that works well, because it's often these children who have less tolerance and need more space. (manager)

A waking night staff member is available in all the services plus sleep-in staff, but this can be supplemented by a second waking night staff member if the children have sleep problems.

A lot of redirection is used to encourage people back into the bedroom, and that's where the second waking staff would be sitting in the room and trying to resettle. Some of our kids are nocturnal, so you maybe get about three hours of sleep out of them, 'cause they don't sleep at home. (manager)

**Assessment placements.** Staying in another location provides opportunities to gather more information about the children's behaviour in a more controlled setting. This can help clinicians provide better treatment and therapeutic programmes.

Children might come in for a one week block. The fifth bed is split between emergency provision and residential assessment, so say we wanted to look at behaviour associated with epilepsy or sleeping or

whatever, we could actually bring a child receiving outreach or assessment in for a block of time to do really intensive observations. We have even in the past done mobile EEGs and [observed] changes in medication. (manager)

*Emergency placements.* The short break service also tries to accommodate children at short notice, but only to those families who are known to them. This can mean negotiating with families who have places pre-booked to see if they will give up their place.

We get emergency requests for children who are already using the service where maybe something has happened, like the situation we have had this morning where we were trying to get emergency respite for one of our young people because mum was not very well at the minute. (manager)

### *Community support: outreach*

The second service strand provided in all three locations is an outreach community support service provided in or from the children's homes. The referring group decide on the number of hours of support the family will receive: this is usually around 8 hours per week up to a maximum of 20 hours.

Across the three services there are variations in the way this service operates. In Glasgow it is predominantly an advisory service to family carers, with a member of staff regularly visiting the home for a defined period to offer guidance primarily on managing their child's behaviours and promoting more positive interactions. Usually these visits take place when the child is at school, but if the children are present the staff may model management strategies.

In Edinburgh and Cardiff, one or two members of staff will come to the home after school or at weekends and usually take the child or young person to activities within the community, but they may also bring him or her to the short break house, or spend time advising the family. The main aim however is twofold: (1) to develop effective behaviour management strategies that can be passed on to the family; and (2) to promote the child's social inclusion through participation in community activities that the families are encouraged to continue. In these two locations, staff work across the two service strands, which helps to ensure continuity in approaches as well as familiarity for the children and families. In Glasgow, the community support staff are based in the short break house and have very close links with staff there.

There are however common features across the three services in their delivery of community support.

*Allocated hours.* Similar issues exist in this service about more families needing the support than can be afforded by the commissioners. One of the aims is to reduce the number of hours that a family receives as things improve for them.

You always have a plan for closure. We have supervision with [manager] on a regular basis where I can say this family is working really well . . . so maybe it's time for me to leave. What I don't want to do is to create a dependency with a family, you want them to cope when you move on. (support staff)

*Clear aims and outcomes.* It is particularly important that families are fully aware of the reasons the service is provided to them.

I would want us to be as clear as we can be about the aims and the outcomes for the outreach service. Sometimes we have particular targets in mind about particular activities or accessing particular places and other times it's appropriate that it's more of a respite break [for the parent]. (psychologist)

**Community activities.** Most of the time is spent outside the family home. This not only gives the parents and siblings a break from caring but is also an opportunity for the children and young people to experience a range of activities.

I would say 90 percent of the time would be out and about because basically we are taking calculated risks, we are testing out things with the children that are difficult for the families to do, and trying to move those behaviours on. (manager)

The longer term goal is for parents to feel able to do these activities as a family.

If we can take them out and get them used to being in people's space out in the community, there's a chance that parents can take them out and do things as a family as opposed to not doing it. And if we can tell them, this is what you need to do, then that's going to be a bonus for the family. (manager)

**Behaviour support.** Staff have to manage the behaviour of the children and young people but also share their insights and methods with the families. This requires sensitive handling.

What parents need is having someone in the house and doing it with you. I think this is a far, far more potent way of doing it really. It's about saying to parents – it's not easy, it's going to be difficult – but to manage your child, you are going to have to do these things. (manager)

One service organized training courses specifically for the parents and the staff involved with one teenager who had very challenging behaviours.

Yes. It was absolutely brilliant because the training was just so targeted. It was such a small group it was just the workers and us, so everything the trainer was doing we could sort of bring the focus back to N and our particular problem. (parents)

### ***Transitions to other services***

The final part of the service model involves helping the young people and families to move on from the services. One strategy is to encourage families to reduce the service they receive as their need for it lessens.

It's actually a positive progression that you see families requesting a reduction [in their service] because other services have come in and they are doing joint work together and they are actually saying we feel supported, so can we reduce our respite [with your service]. (social worker)

Another option is for the family to be referred back to the referring group and it becomes their task to find another form of less intensive support service if this is required. In these instances, Action for Children will share its experiences and expertise with the new agency.

*Adult services.* In any case, once the children become 19 years of age, they have to leave the services. The challenge then is to find comparable provision in adult services. Funding is a big issue.

[For children] health pays half the bill for the service here, but health doesn't pay into packages of care for adult services at all, unless they define a health need which doesn't cover mental health or behaviour. (social services)

But adult services are often not equipped to meet the demands these children place on existing provision in terms of housing or staffing. In part the solution is for adult services to engage in service developments similar to those that children's services have undertaken.

I think a piece of research that illustrates what works well and why it works well can then inform planning in adult services, because at the moment we say it does, but some really clear indicators about what works well, and why, might help with their planning. (health manager)

*Further developments of the service model.* Finally in the interviews and group discussions a variety of issues was identified through which the model of service could extend its reach to more families if resources permitted, offering more opportunities to the young people, and indeed transforming the service into other forms of family support such as training courses for parents and leisure-style breaks for the children and young people. A particular emphasis was on early referrals.

I think the referrals come to us too late, it's almost crisis intervention. It's the five to 12 age group where I think there is a gap. Parents manage but aren't really managing, they just think they are, and I think if we could capture more of those parents you might avoid the behaviours that can happen when they hit puberty for instance, then you might avoid more breakdowns of families. (manager)

## Discussion

The consultation meetings confirmed the high regard that participants had for the three services which endorsed the rationale for focusing on a successful service in order to document the features contributing to its effectiveness. The intricacy of the resulting service model is not surprising given the complexity of the children and parents, and this study both confirms and extends recommendations and guidance around the provision of short breaks (Staley, 2008) and research undertaken with families (Beresford, 2009; McConkey et al., 2004).

This detailed exposition of the main service features can help to clarify the distinctive nature of this type of specialist provision in comparison with other short break services that are aimed at families with less complex needs. Moreover the model provides a framework against which such services can be monitored and evaluated, as well as assessing their quality and 'value for money'. It also provides a blueprint to enable similar services to be developed elsewhere.

A number of features within the model are worth emphasizing. The services are for selected children and families with complex needs – those considered by a multi-agency panel to be the 'most needy'. This provides an equitable referral system and protects service personnel from charges of favouritism. The services strive to assist the children to become more competent and to reduce their challenging behaviours. The staff have particular expertise and experience around behaviour management, which means they are well suited to advise and train others, such as

parents or staff in other services. This contributes to the throughput of families within the services: as their needs lessen they can be referred for less intensive support.

The service aims to forge trusted relationships with parents, and through personal contacts offers them emotional as well informational and tangible supports. Merely providing a break to parents is insufficient in reducing the ongoing stresses they experience (McNally et al., 1999). Parents also gain personally from improvements in their children and the hope that this offers (Lloyd and Hastings, 2009).

The amount of service provided to families is carefully matched to their needs and can be increased and decreased. This requires careful judgement and negotiation by social workers and service staff, but the trusted relationship built with parents seems to avoid much of the confrontation that seem to be more typical in parents' relationships with services (Lake and Billingsley, 2000). Moreover the matching of services to family needs rather than parental 'wants' is a potent means of ensuring cost-efficiencies (Roberts, 2001).

The analysis of the service model confirms the need for specialist short break services to be integrated within a wider service network of supports to families and children. They cannot function as 'stand-alone' services. The difficulties associated with multi-agency working are well known (McConkey, 2006), but equally these services and others like them demonstrate that it can be achieved. However the shift in commissioning towards individualized funding packages could threaten such arrangements (Carr and Robbins, 2009).

Various improvements to the model were mentioned, notably the need for earlier referral and preventative work rather than waiting until a crisis is reached. In part this falls outside the eligibility criteria agreed for more specialized services, but the danger is that no other agency is available or equipped with the resources and expertise to undertake preventative strategies; this is a well recognized failing in British health and social care provision (Sloper, 1999). Likewise, the dearth of comparable support services once young people reach adulthood is a major concern to parents especially (Mencap, 2010). In part this may be due to the lack of familiarity among adult service planners with the new forms of provision that have evolved in children's services in the past decade. In that case, the documentation of innovative practices can serve yet another purpose.

Finally, further studies are ongoing into the outcomes achieved by the service and the costs associated with it. If comparable exercises were to be undertaken with other forms of family support services, then commissioners would be better informed about achieving value for money (Holmes et al., 2010).

## **Acknowledgements**

We are very grateful to the service managers, staff, parents and community personnel who so willingly took part in the focus groups for sharing their experiences and insights with us.

## **Funding**

This research was funded by Action for Children. Roy McConkey's post at the University of Ulster is jointly funded by the Health and Social Care Board for Northern Ireland.

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