

Working Outside the Box:
An Evaluation of Short Breaks and Intensive
Support Services to Families and Disabled
Young People whose Behaviour is
Severely Challenging.

Summary Report

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Fuller details of each strand of the evaluation are contained in a series of papers that accompany this report. They are:

1. Supporting Families with Disabled Young People whose Behaviour is Severely Challenging: A Review of Literature.
2. An Appraisal of the Service Model offering Short Breaks and Intensive Support to Families and Disabled Young People whose Behaviour is Severely Challenging.
3. The Short Break and Intensive Support Services provided by Action for Children in Cardiff, Edinburgh and Glasgow
4. The Characteristics of Children and Families Using Short Break and/or Intensive Support Services
5. Profile of staff employed by Action for Children in the three Intensive Support and Short Break Services
6. Perceptions of Short Break and Intensive Support Services: The perspectives of stake-holders across three services.

These are available to download from the following website:

www.science.ulster.ac.uk/actionforchildren.

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Overview and Executive Summary

The summary report brings together the main findings from the evaluation undertaken of three Action for Children services in Cardiff, Glasgow and Edinburgh. These provide specialist short breaks and intensive support services to families and young people with developmental disabilities and whose behaviour is severely challenging. This summary report describes the aims of the evaluation and the methodologies used. A series of more detailed reports describe the findings which are briefly summarised in this report.

The model of service: First a literature review was conducted to identify current thinking and best practices in meeting the needs of these children and families. Second, a detailed analysis made of the model of service that has evolved in the three chosen locations. This has various unique aspects foremost of which are the close partnership working with commissioners and partner agencies, and the combination of Short Breaks with support services provided from or in the family home by the same staff team.

Staff working in the service: Details of staff were also collated for the three services most of whom are employed on a part-time basis to provide flexibility in assigning staff to children and families. Nearly all staff hold some form of higher qualification and they have access to regular and varied training courses.

Families using the services: Information was obtained on 123 young people and families who use the services or had done so in the previous two years. The families came predominantly from poorer backgrounds, with a high proportion of lone parents. They lived mainly in rented accommodation and were dependent on social security benefits. Many of the family carers who received the services had high levels of personal needs and with nearly half, there is some risk of family break-up and two in five children were thought to be 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 Intensive Support tended to be provided.

Children using the services: Overall more boys than girls used the services, especially the combination of Short Breaks and Intensive Support. The children were mostly teenagers although many had accessed Intensive Support at a younger age than they did Short Break services. Nearly all attended special schools. 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 that were currently rated as severe or moderate, of which sleep problems were the most frequent. Children receiving both Short Breaks and Intensive Support tended to have more behaviour problems and to be on medication for this.

Changes in children and families: Ratings were made by key-workers of changes in the children and families. Over the past six months, sizeable proportions of the children were reported to have shown some improvements in their communication and personal care. Likewise around half the children had improved in terms of their stereotyped behaviours and aggression to other persons. Children who had received Short Breaks tended to have improved behaviours and especially if they received a greater number of nights per annum. This was linked with improved ratings on parental well-being. But for small proportions of children the risk of moving out of the family home had increased rather than decreased. These estimates may underestimate the amount of change that had occurred in children and families since they commenced the services. Ratings taken over a longer time period would better reflect this. But by contrast, they may over-estimate the change that families experience in that improvements may be realised more in the service settings than at home when there is no staff support.

Personal experience of the services: A further strand of information gathering entailed 48 individual interviews with the main stake-holders who were personally involved with a

selected sample of 17 children – the primary carer; the key-worker in the service and a representative from one of the partnering agencies, such as a social worker. The aim was to gather rich qualitative data to illuminate their experiences of short breaks and intensive support services. From these accounts an analysis could be made of the dominant themes that typify their perceptions of these services and the impact they have on the lives of families. The over-riding opinion of these services by all stake-holders was very positive and respondents identified five sub-themes that justified this appraisal.

- ☆ The way services managed the complexity of the children, family and services.
- ☆ Coping with ambivalence among parents in their use of the services.
- ☆ The focus the services had on building and sustaining relationships.
- ☆ The various benefits they brought to the children and families.
- ☆ Planning for an uncertain future.

These themes are examined using quotations from the range of respondents across all three services which further validated the impact of the services on families.

Views of the young people: These opinions were complemented by information gained from talking with or observing the young people mostly when they were on short breaks. Although they liked staying at the house, they liked best the chance to go out and do things in community. A range of activities were reported but not many involved personal contact with other people. Their main dislike was missing their family and home. The person-centred approach to working with the young people is a major plus in making their stay a beneficial experience for them and goes beyond merely looking after the children so that their parents have a break.

Conclusions

Seven main lessons can be drawn from the study to inform service delivery and commissioning.

- ☑ The services are specialist provision for selected children and families with complex needs. The staff have particular expertise and experience. The services are aimed at the most needy persons.
- ☑ Strong partnerships are maintained with commissioners and other service providers to provide co-ordinated packages of support to families. They cannot function as 'stand-alone' services.
- ☑ The amount of service provided to families is carefully matched to their needs and can be increased and decreased. This not only ensures cost-efficiency but it is in the interests too of the children and families.
- ☑ Short breaks and intensive support help children become more competent and reduce their challenging behaviours. The expertise and experience of staff means they are well suited to advise and train others, such as parents or staff in other services. Parents also gain personally from improvements in their children.
- ☑ Parents benefit when their personal needs are identified and trusted relationships are forged. Merely providing a break is insufficient to help reduce the stresses they experience.
- ☑ The young people have increased opportunities for participating in community activities which is a major achievement given the children's behaviours and reputation but their social inclusion remains limited.
- ☑ No clear pathways exist for the transition to adult services. Major improvements are needed in the way adult services provide for these young people and their families.

Recommendations

The report ends with a series of recommendations of particular relevance to Action for Children but are probably applicable to similar services elsewhere.

- The services need to debate and reflect on the extent to which they portray themselves as specialist providers and seek that acknowledgement from commissioners and partners.
- The services should pro-actively re-assess the quantum of service provided to the children and families and specify the outcomes they are working towards.
- A wider range of training and personal development opportunities should be developed for families.
- The services should develop IT systems that more readily identify the outcomes for children, parents and siblings.
- The services should increase the opportunities for building social relationships among the children and young people and with others in the community.
- Action for Children, in association with their partners, should prepare plans for comparable services to meet the needs of 16-25 year olds and their families.

The demand for specialist services to support families whose children have complex needs shows no signs of abating. Although the policy context is agreed, our knowledge of how best to support families is still accruing. And in times of economic stringencies, it is all the more crucial to identify the essential elements for delivering effective and efficient services. This report hopefully goes some way to doing just that. The title of the report comes from one mother's comment on the service she received from Action for Children:

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.

With that spirit, the future is more manageable.

Acknowledgements

An evaluation of this sort is only possible with the whole hearted co-operation of many people. We are very grateful to the members of the national and local steering groups for their guidance and wise counsel throughout the evaluation. Also to the service managers and their deputies for the organisational arrangements and information gathering which they undertook so promptly and efficiently. Our thanks especially to the parents, young people and staff who took part in the focus groups and interviews.

The art work on the cover was drawn by young people attending the three services.

Disclaimer

The views expressed in this report are those of the author and should not be taken to represent the views of Action for Children. Our preferred term is 'short breaks' but we have retained the word 'respite' when used by informants in the course of the study.

Introducing Action for Children

Action for Children has become a major provider of services to disabled children in partnership with local authorities, PCTs and Health Boards across the United Kingdom. Currently 71 projects provide specialist services for disabled children with complex impairments. This is in addition to over 9,000 disabled children accessing their inclusive children's services. A significant number of children using Action for Children's current services have severe learning disabilities and associated challenging behaviour, complex health needs or life-limiting illnesses.

Their specialist disability services include domiciliary care (home support), residential short breaks (which accounts for over half their commissioned services for disabled children), residential care and schools, Children's Centres, transition support, key working, advocacy, family based short breaks, specialist and inclusive play and leisure activities. Whether community based, family based or residential, all the services are tailored to meet the aspirations of individual children and young people.

The vision of Action for Children is:

"of a world where all children and young people have a sense of belonging, and are loved and valued, a world where they can fulfil their potential, shape their destiny and experience the joy of life".

The organisation's three core values are:

Passion: *we are driven by our desire to help children and young people overcome injustice and disadvantage.*

Equality: *we believe all children and young people have equal worth and equal rights.*

Hope: *we believe in a child or young person's potential, no matter what they have experienced or what they have done".*

Short breaks and intensive support

Action for Children provide intensive short breaks 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. The services are in three locations:

- Stoneside Family Support, Glasgow
- Gilmerton Road, Edinburgh.
- Cardiff Breakthrough.

These are specialist support services to families, whose main rationale is stated by Action for Children as follows:

"Without intervention families and school placements can break down and children either move into residential schools and/or homes. This is at a great cost to the Local Authorities and in many cases they fail to meet the real needs of the children and young people who become distanced from their families and communities".

Hence the dual aims of the services are described by Action for Children as:

- "1. To support disabled young people and their families to stay together.*
- 2. To keep the young people included in their communities by for example, supporting them to use universal local facilities."*

(Appendix 1 gives further details of the services as described in their documentation).

The model of services offered to families is aimed at addressing the exceptional needs of their children, mostly in relation to the challenging behaviours they display or have displayed in the past. The services provided can be grouped into three broad categories.

- **Short Breaks:** The children and young people stay overnight in a homely residential unit with a small number of other children (up to five) for an agreed number of nights per annum (usually from two to seven nights at a time). These stays not only provide the families with a break but also give the young people an opportunity to experience being away from home and perhaps learning to do more for themselves, as well as taking part in a range of activities of their choice within the house and in the community.
- **Intensive Support/Outreach:** This entails staff working with the children and young people in community settings both as a means of giving the family a break but also in helping the young person to manage better their behaviours and enabling them to access community facilities. Parental guidance and training in managing behaviours is also provided.

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 may also bring him or her to the short break house, or spend time advising the family. The main aim however is two-fold: 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 intensive support staff are based in the short break house and have very close links with staff there.

- **Combination of Intensive Support and Short Breaks.** Some children and families may access both services, either at the same time, or else they will start with one – usually Intensive Support - and then move on to the other.

Hence, three groupings could be identified: those who only received short breaks; those who only had received intensive support and those who had or were receiving both short breaks and intensive support.

Evaluation of the Services

Action for Children commissioned the University of Ulster to undertake an evaluation of the three services. There were eight main strands to the Review.

1. Undertaking a review of literature so as to contextualise the evaluation within national and international experience of providing intensive and specialist support to families.
2. Describing the key components of the model of service that is common across the three locations.
3. Profiling the staff working in the services and the training they had received.

4. Documenting from information contained on files, the characteristics of the young people and families who use the services. This is done for the three locations (primarily for internal use by Action for Children) but also by those families in receipt of different types and combinations of services.
5. Estimating the changes that key-workers have perceived in the children and young people, and their families from participating in the services.
6. Assessing the impact of the services from the perspectives of the young people, family carers, staff working in the services and professionals in partnering agencies who refer or offer ongoing support to families.
7. Obtaining young people's perceptions of the services and the social inclusion activities in which they participated.
8. Identifying the costs involved in providing these forms of services.

An iterative, participatory approach was followed. As well as a national steering group of senior Action for Children staff, a local steering group was formed for each of the three services consisting of representatives of all the main stake-holders – service managers, front-line staff, family carers and the partnering agencies. Their main roles were:

- To provide guidance and advice at all stages of the Review process.
- To identify key stake-holders (such as the young people, families, staff) and facilitate communication with them.
- To encourage information sharing across and within stakeholder groups.
- To assist in decision-making throughout the Review.
- To ensure that all information gathered by the consultants is done ethically.

Each stage of the Review was informed and planned in conjunction with Steering Groups. The information gathered within the review was shared with them and their views sought. This provided validation of the findings as well as identifying recommendations arising from the data gathered.

The review process aimed to be transparent and participative. A web-site¹ was designed to keep interested parties informed of our progress and information sheets about the Review were distributed to all families and service staff. Formal ethical approval was not sought as this study constituted a service audit but ethical guidelines were followed especially with respect to informed consent, assurances of confidentiality and the independence of the evaluation from the provision of the services.

Further details of the review methodology is given in the following sections, each of which focuses on a main strand in the evaluation. Appendix 2 summarises the lessons that members of the national and local steering groups drew from the experience and as a means of informing future evaluations within the organisation.

A final section of the report identifies ways in which the services could be improved and the implications for implementing this model of service elsewhere.

¹ <http://www.science.ulster.ac.uk/actionforchildren/index.php>

Strand 1: Review of Literature

The aim of the literature review was to draw out the main implications for practitioners in the design and delivery of support services to families who have a child with learning (and other developmental) disabilities and challenging behaviours. It is structured into four sections and provides a context and rationale for the model of service that has been developed in the three locations (see Report 1).

1. Policy: The first section summarises the policy context within the United Kingdom and notes the strong commitment from Central Government and devolved administrations to support families through a series of new policy initiatives although the impact of these remains to be seen. The need for increased provision of short breaks (respite) to family carers is well accepted by Government with commitments for increased funding being made available specifically for these services. However this investment comes with some identified priorities regarding the nature and style of breaks to be commissioned with more of a focus on the outcomes for carers and young people. In the aftermath of devolution, ongoing monitoring of policy implementation is required with particular reference to variations across the four nations.

2. Family support services: The second section focuses on the evidence-base for the provision high-quality support services to families: firstly in terms of overall service delivery and secondly in relation to short (respite) breaks. Remarkable advances have been made in the development of policies for supporting families and a striking consensus has been achieved over the style and format of services that are needed and the outcomes they aim to attain. New forms of services are taking shape albeit for some rather than for many families but it is a measure of the challenge ahead that so much remains to be done to extend and improve present provision. Of particular note also is the limitation of much of the extant literature of demonstrating the impacts on children and families.

3. Challenging Behaviours: The third section of the review focuses on challenging behaviour and the support service required by families who face these challenges. Although only a minority of children with disabilities exhibit severely challenging behaviours they do impact greatly on families and can lead to families seeking out-of-home care. This is compounded when services fail to deliver the supports that families find helpful. The implementation of systematic programmes for managing behaviours has been of assistance and parents would benefit from training in these approaches. There is a need for greater investment in locally available specialist provision to prevent children leaving the family home.

4. Costs of provision: The fourth section examines the costs of providing short break services with a discussion as to how assessments around cost-benefits might be made. Our understanding of the cost-benefits resulting from short break services is still in its infancy. There are a number of promising lines of enquiry but given the commercial sensitivity of this information in the competitive tendering process used by many commissioners, it will be difficult to encourage agencies to share full details of their income and expenditure. Moreover as governmental funding becomes more constrained, there is a danger of indiscriminate reduction across all services without due regard to the differential benefits that different services can bring to the people using them. This will perpetuate inefficiencies within service delivery, reduce the overall cost-benefits of short break services and ultimately lead to greater costs in the longer-term.

To conclude, although there is a growing literature relating to specialist family support services with valuable indicators of what needs to be done, there is as yet scant documentation around the type of services that are operational and limited evidence from empirical studies of their impact on families.

Strand 2: Describing the model of service

A first step in the evaluation was to describe in detail the common features of the specialist service model that operates across the three settings. This in-depth analysis has been rarely undertaken of service provision as the focus tends to be on assessing the outcomes of services rather than a detailed description of their functioning.

The term 'service model' covers the following:

- The aims, objectives and aspirations of the service and the outcomes it is striving to achieve for the specific client group of young people and families.
- The values and ethos underpinning the supports that are provided.
- The nature of the supports provided by the service, its staffing, activities undertaken and facilities provided.
- The inter-faces the service has with other services.

In sum, the aim was to provide a conceptual service model that is more detailed than the broader philosophical models in the field of child care or disability (such as the 'social', 'medical' or 'rights' model of disability). But from this conceptual model, more specific models could be derived, such as staffing and financial models. The features that are common to all child and family services, such as child protection, health & safety, equality & diversity, underpin all the services but they are NOT highlighted within this model with its focus on short breaks and intensive supports for families.

The rationale for having an explicit and detailed model of service can be summarised as follows:

- It creates a common language and shared understanding among the various stake-holders engaged with the Model.
- It documents how the monies received by the service are expended.
- It offers a framework against which the service can be monitored and evaluated, as well as assessing its quality and 'value-for-money'.
- It provides a blue-print to enable similar services to be developed elsewhere and for other client populations.

The process for documenting the service model

Three sources of information were used to gather the stake-holder's perceptions² of the service model as developed by Action for Children.

1. 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.
2. 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. A second key informant was also identified in the Scottish services who gave more detailed information about the intensive support offered in the community and family homes. These five interviews were audio-recorded and transcribed verbatim.
3. Based on the above information, diagrams were prepared that tried to capture the main features of the service model that were common across the three locations. These were then used as a basis for discussion with the Steering Groups for each of

² All the participants were assured of confidentiality and were asked to respect this when speaking with others about the group discussions. Parents were assured that their views would not affect the services they received now or in the future. Consent forms were signed by all participants.

the services. Additional persons were invited by the service managers to attend these meetings so that the range of stake-holders were represented. In all, around 30 persons attended the groups, including mothers and fathers, front-line staff, service managers and deputies, clinicians, social workers, health and social service managers. These groups epitomized the partnership approach that underpinned the development of the services and their ongoing delivery. Moreover they provided an internal validity check of the model as all participants in varying ways had contributed to it and were actively engaged with its daily operations. The discussions, which lasted around 80 minutes in each location, were audio-recorded and transcribed.

4. The final stage of the process involved members of the National Steering Group reflecting on the model as presented in this document. This served as further confirmation that the main features of the model have been captured through the analysis of interview and focus group data. Also members of the local steering groups had an opportunity to comment on the report as further confirmation of the Model which they had helped to define.

Context in which the services operate



Figure 1: The Contexts and Partnerships underpinning the Model

Before describing the model of service, it is important to set it within the broader service and support context from which it has emerged. There are two aspects to this: 1) the context provided by Action for Children with its common core values and ethos for its services. 2) The partnerships with other services in the localities in which the services operate. The particular features are summarised in Figure 2.

1. Action for Children Services³: The specific supports the organisation provides to the intensive support services include:

- Policies and procedures they have implemented in relation to their core ethos,
- Opportunities for service/project managers within a region to meet formally. Informal advice and guidance is also available through this network.
- Regular induction, inservice and refresher training for staff.
- Accredited training in behaviour support, such Pro-Act Scip@UK

2. Local Partnerships: The outer ring of supports in Figure 1 represent the agencies outside of Action for Children with whom the services work in partnership. These

³ Further details are available at: <http://www.actionforchildren.org.uk/>

include the Learning Disability (LD) Teams and the Child and Adolescent Mental Health Teams (CAMHS). These consist of clinical psychologists, psychiatrists, nurses and various therapists such as Speech and Language Therapists and OTs. One service also has links with community psychology. The services may link with these teams and clinicians in relation to individual children.

Special schools and also mainstream schools are engaged with the services. Also educational psychology may have an involvement through the referring group.

The services may also have link with other family support services in their area; notably home support (domiciliary services), befriending schemes and other short break providers. These are services which the families may have previously used or to which they can be referred.

There are also opportunities for managers of various child and family services within an area to meet to co-ordinate their work.

Finally a central partner is the family social worker who not only handles the referral to the services but maintains contact throughout the family's placement.

Note: It was beyond the scope of this review to examine in detail, the inter-relationships among these agencies and how their contributions to the overall network of service delivery might be enhanced. Nonetheless it does seem to be a necessary means of providing a family with the co-ordinated support they require across agencies and professionals.

Key features of the short break and intensive support service model

The six key features of the service model (i.e. boxed areas) to emerge from the consultation process are summarised in Figure 2.

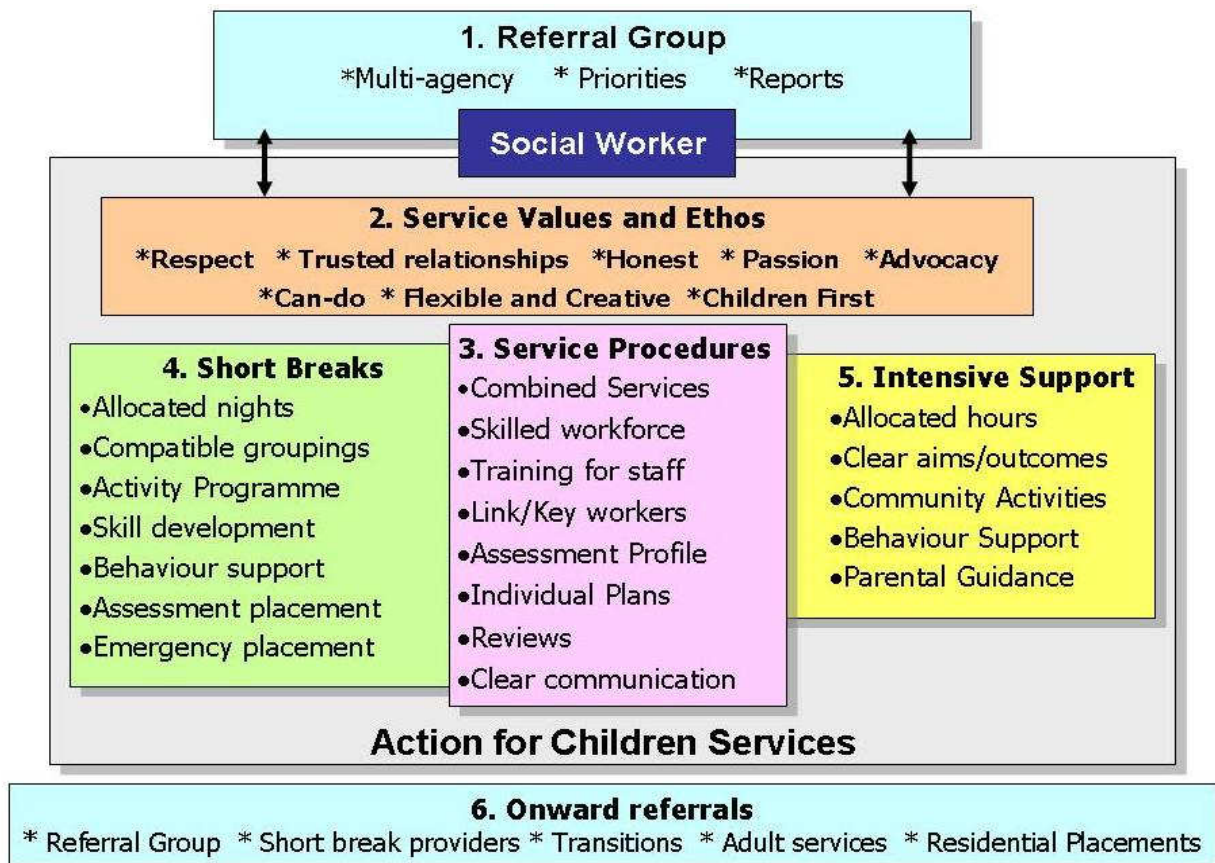


Figure 2: The Model of Intensive Support to Families and Young People

A number of over-arching points should be noted.

- The Action for Children services are located within an overall service context (Boxes 1 and 6): they are the 'sandwich' within the figure. The model of service that has evolved is predicated on a multi-agency service culture and context that works in close partnership with Action for Children services. This theme is further developed later in this report.
- The services are specialist provision and are available only to selected families within defined geographical areas.
- The focus is on supporting the family as a unit and not just on the young person.
- There is an expectation that children and families will move on as their needs change and certainly once the young people become adults. This ensures that the services have a through-put and places do not become blocked.
- The complexity of the service that has evolved is an 'extra-ordinary' response to the challenges that the children and families have presented to the services.
- The service model is dynamic and responsive to the needs of individual children and families. Certain aspects are more critical for some families than others. Moreover the model is likely to continue to evolve in response to changing needs and circumstances.

Figure 2 summarises the significant elements within the six core areas of the service model. Each element is described more fully in an accompanying report⁴. As far as possible, the elements in the model are described using the words of the different stakeholders who participated in the focus groups. The validity of the model is further assessed within other strands of the evaluation (see later sections).

In summary, this specialist model of service is complex given the needs of the children and families that it seeks to address. The detailed exposition of its main features is intended to clarify the aspects that distinguish it from other short break provision aimed at children and families with less complex needs. Moreover as is confirmed later, the services are perceived to have been successful in retaining children within their families and furthering their participation in community activities; two outcomes that have been difficult to achieve with young people who have severely challenging behaviours. Hence an intricate and integrated service model, underpinned by a defined ethos, is fundamental to success in supporting families who face significant challenges.

⁴ Report 2: An Appraisal of the Service Model offering Short Breaks and Intensive Support to Families and Disabled Young People whose Behaviour is Severely Challenging.

Strand 3: Profile of staffing

In all 89 contracted staff were currently employed (as at 1st May 2010) or had been previously employed (within the last two years) in the three Action for Children services in Glasgow, Edinburgh and Cardiff. Information on staff characteristics was provided anonymously by service managers using the HR database held by the organisation. Table 1 shows the number of staff in the three services.

Table 1: The number and percentage of contracted staff in the three services over the past two years

Service		In post	Left	Total
Edinburgh, Gilmerton	N	26	16	42
	%	61.9%	38.1%	100.0%
Glasgow, Stoneside	N	24	7	31
	%	77.4%	22.6%	100.0%
Cardiff, Breakthrough	N	14	2	16
	%	87.5%	12.5%	100.0%
Total	N	64	25	89
	%	71.9%	28.1%	100.0%

Some notable points include:

- The staff are predominantly female (88%) with 11 males (12%) having been employed: eight currently. Most staff are aged under 30 years. The median length of service of staff currently in post is 3.8 yrs (range 9 months to 19.7 yrs) but a quarter of staff have been with the services for five or more years.
- Of the 64 staff currently in post, 8 (13%) held some form of managerial or senior post; 47 (72%) were Project Support staff, 4 (6%) were in administrative or housekeeping roles and 5 (8%) were employed as casual staff (all within the Glasgow service).
- Around 40% of the staff (N=25) were on full-time contracts but half (N=30) held part-time and 6 'zero-hour' contracts. Less than one-third of the project support staff (N=14:29%) had full-time contracts; most held part-time or casual contracts (N=35: 71).
- The part-time staff worked a median of 9 hours per week (range 2 to 37 hours).

Staff Qualifications and Training

One-third of the staff hold a degree; seven have a nursing qualification and two a social work qualification. Over half (including some with degrees) have taken N/SVQ Level III plus HNC in social care; while a further six persons have N/SVQ level III only and three hold HNC in Social Care only. Of the remaining four staff, only one has no qualification. The people who left the services tended to be those with degrees.

In 2008, staff attended a median of four days for training (range 0 to 12 days) and the comparable figures for 2009 were a median of 3 days (range 0-14 days). In 2008, staff attended a total of 346 training days and 279 days in 2009.

Staff absences

Nearly half the staff (47%) had no absences recorded in 2008 and 38% had no absences in 2009. Of those who were absent, half were for 1-3 days but 10 staff had absences exceeding 14 days in 2008 and eight for absences in excess of 14 days in 2009.

Leavers

A total of 25 staff had left within the last 28 months. This amounts to nearly 40% of those in post as at 1st May, 2010. The annual turn-over is around 15% and is more marked among casual staff and among staff aged under 40 years. Staff who left had been employed for a median of 2.7 years (range 5 weeks to 13 years). In all 12 staff left to take jobs with other organisations; 3 to other jobs with Action for Children services, 4 for personal reasons and 2 had emigrated. One person's casual contract had been terminated as no shifts had been worked.

Conclusions

Although there were some variations in the characteristics of staff across the three services, the overall picture is broadly comparable. The services employ a well-trained workforce with the bulk of staff working in front-line positions, mostly on part-time contracts in order to give flexibility in staffing shifts. The low proportions of males and staff from ethnic minorities is note-worthy especially given the clients who use the services (see next section). Turn-over and absence rates seem lower than that experienced by the social care sector but the figures here would be more meaningful if comparisons could be drawn with other Action for Children services or comparable short break services.

Fuller details of staffing and their training is contained in an accompanying paper⁵.

⁵ Report 4: Profile of staff employed by Action for Children in the three Intensive Support and Short Break Services

Strand 4: The characteristics of the children and families using the services

With assistance from the Steering Groups, a pro forma was developed to capture demographic information about the children and families who either were in receipt of services on 1st May 2010 or had left in the past two calendar years. The key-workers were then asked to collate the information using the computerised data base (E-Aspire) maintained by Action for Children for all its service users; the children's paper files or from their own knowledge of the children and families. The data provided was checked by senior staff or managers. In all, 123 children and families were included in these analyses. Full details are contained in two supplementary reports⁶: one gives the data for each of the service locations and a second, details the variations in characteristics across the three types of services provided: short breaks only, intensive support only and a combination of both. The numbers within each grouping are shown in Figure 3 and a summary of the main characteristics follows.

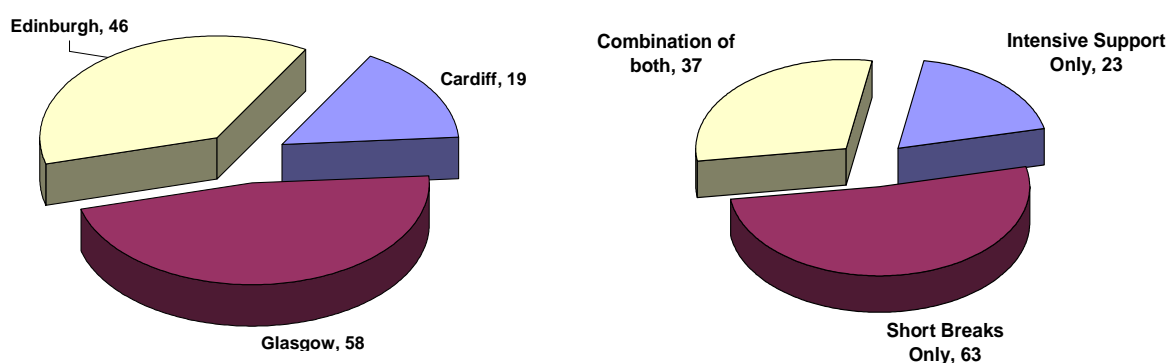


Figure 3: The number of children and families in the analyses by location and by the types of services they received.

Family characteristics: The families predominantly have low incomes and a high proportion were lone parents. They lived mainly in rented accommodation and were dependent on welfare support benefits perhaps as a consequence of full time caring. Many of the family carers who received the services had high levels of personal needs although in only a few instances did these seem to be related to the types of services provided to them. 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 Intensive Support tended to be provided.

Child characteristics: Overall more boys than girls used the services, especially the combination of Short Breaks and Intensive Support. The children were mostly teenagers although they accessed Intensive Support at a younger age than they did Short Break services. Nearly all attended special schools. 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

⁶ Report 3: The Short Break and Intensive Support Services provided by Action for Children in Cardiff, Edinburgh and Glasgow

Report 4: The Characteristics of Children and Families Using Short Break and/or Intensive Support Services

Short Breaks and Intensive Support tended to have more behaviour problems and to be on medication for this.

Services provided: The two forms of services – Short Breaks and Intensive Support - are available to most families with only a small proportion using Intensive Support only. Children are around 10 years of age when they first access the services with a wide variation in the length of time they had used Short Breaks services: the median was around two years. For those who had received Intensive Support services but had now left, the median length of time they received the service was also two years.

The quantum of service provided also varied widely across families. More Short Breaks nights are provided to families at a greater risk of family breakdown and who have received breaks for more than two years. Yet the extent of the child's current challenging behaviours or their levels of functioning was not predictive of the number of nights or hours of support the family received.

The annual turn-over in the Short Break services is around 10% mainly due to the children reaching the upper age limit for this service. Children leave Intensive Support when the objectives have been attained or when they transfer to Short Breaks.

Variations across the three locations

The children using the services in the three locations show very similar characteristics which is not unexpected in that the services are designed to meet the needs of children, and more especially teenagers, with more severe or complex needs. However the young people supported by the Cardiff service appear to have higher levels of challenging behaviours, with the Edinburgh service reporting lower levels but greater than those in the Glasgow service. Nearly one-third of the children overall were on medications for mood and behaviour rising to over half for those receiving both Short Breaks and Intensive Support. The smaller number of children in Glasgow receiving these medications may reflect the lack of access that these children have to consultant psychiatrists compared to the other two services.

The variations across families that are apparent across the three services may in part arise due the different socio-economic characteristics of the locations in which the services are based. For example, the area around Edinburgh is generally more affluent than Glasgow. But it is also possible that some of the variation arises from the referrals made to the project and perceptions of their role by commissioners and referrers. Hence the Cardiff service reports higher levels of family problems. But the smaller numbers in this service means that differences should be treated with caution.

Although the three services share a common ethos and models of provision, there are some notable variations in the delivery of the services in the three locations. This is to have arisen through the local commissioning process and the range of referrals made to the individual services. This will also be influenced by the availability of other services within the locality. The variation is further compounded by the length of time the service is operational in that criteria may change over time but earlier service-users may continue to avail of it with a different pattern of needs.

Conclusions

The detailed profile of the children and families contained in the two accompanying reports illustrates both the variety and complexity of needs that the three types of services seek to address in the three locations. This is not only in terms of the needs of the children and young people but many also come from complex family situations.

Ideally it would have been informative to have comparator data from families receiving less intensive forms of support services within other Action for Children services or from other providers. A common data-set across services would make such comparisons easier and could link with indices of change in the children and families.

Strand 5: Perceived changes in children and families

The pro forma used in Strand 4 was also used to gather information on pertinent indicators of changes that might be expected to have occurred in the past six months or since the family joined the service if within the last six months. This included changes in the children's communication and self-care skills, their challenging behaviours and the risk that they may be placed away from the family. Changes in parents and family were also rated.

Using file data on goals set and individual programme plans, the key-workers for each child or young person were asked to rate the children on a simple three-point scale: improved, stayed the same or worsened in the areas noted above. The following tables summarise the changes recorded.

Table 2: The number and percentage of children rated as having changed in communication and self-care skills over the past 6 months.

		Some improvement	Same	Worse	Total
Communication	Count	38	49	1	88
	%	43.2%	55.7%	1.1%	100.0%
Feeding self	Count	31	58	0	89
	%	34.8%	65.2%	0%	100
Personal Care	Count	38	51	0	89
	%	42.7%	57.3%	0%	100
Continence	Count	30	57	1	89
	%	34.1%	64.8%	1.1%	100

Overall more than 40% of the children were deemed to have improved in one or more areas and the improvements tended to be greater in communication and personal care as Table 2 shows. Compared to children who had Intensive Support only, higher proportions of children who attended Short Breaks were rated as showing improvements in their self feeding (40% v 0%) and personal care (48% v 8%) ($p < 0.05$). However a greater number of nights per annum was not related to improvements.

Similar ratings were made for challenging behaviours that the children were recorded as displaying and the results are displayed in Table 3.

The behaviours are listed according to those behaviours that had improved; thus more children were rated as improved in the hurt they may cause others and in stereotyped routines. Fewer had changed in terms of screaming, self-injury and depressive mood although some had. Few behaviours had worsened although this was more marked with sexualised behaviours than with other behaviours and is linked with the age of the young people.

Higher proportions of children who received both Short Breaks and Intensive Support showed improvements in self-injury and a greater reduction in stereotyped, repetitive behaviours ($p < 0.05$). Otherwise the improvements in other behaviours were unrelated to the type of service.

Table 3: The number and percentage of children rated as having changed in last six months in the challenging behaviours listed.

Behaviours		Rating			Total [^]
		Some improvement	Same	Worse	
Hurts Others	Count	25	22	1	48
	%	52%	46%	2%	
Stereotyped*	Count	29	32	0	61
	%	48%	52%	0%	
Hyperactivity	Count	21	25	1	47
	%	45%	53%	2%	
Sleep	Count	24	31	0	55
	%	44%	56%	0%	
Sexualised behaviour	Count	5	5	4	14
	%	36%	36%	29%	
Damage to property	Count	13	23	2	38
	%	34%	61%	5%	
Screaming	Count	8	17	0	25
	%	32%	68%	0%	
Self-injury*	Count	11	24	1	36
	%	31%	66%	3%	
Depression	Count	5	12	1	18
	%	28%	67%	6%	

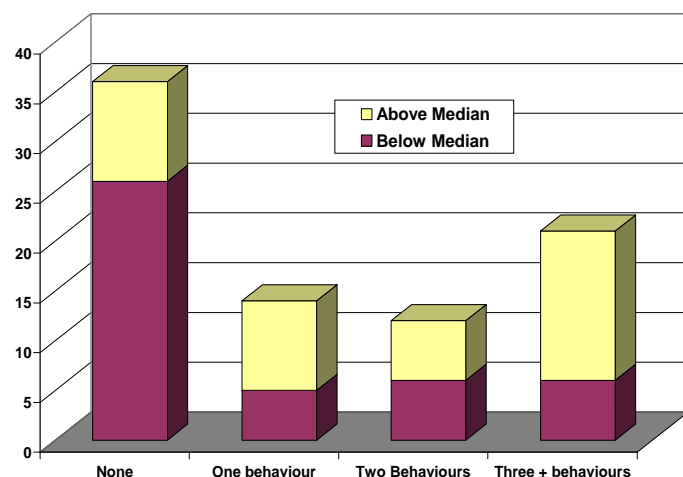
[^] The number of children for whom this had been noted as a problem

* $p < 0.05$ for differences in these behaviours across the types of services

A count could also be made of the number of behaviours that were rated as having improved. Across the three types of services a similar pattern was found. Children showed a median of one improved behaviour but the range was from 0 to nine behaviours improving.

But as Figure 4 illustrates, children who received more short break nights per annum tended to show significantly more improvements in the number of behaviours that were rated severe or major problem. However the number of hours of Intensive Support was not associated with ratings of improvements in behaviours.

Figure 4: The number of children showing improved behaviours by the median number of Short Break nights received.



The key-worker also assessed if there had been any change in the risk that the child might have to live away from the family. Of the 34 children deemed to be at some risk, with eight (24%) the risk had increased whereas for four (12%) it had improved (with others the risk was unchanged). The numbers are too small to establish reasons for the increased risk.

Improvements in families

Similar ratings were also provided by key-workers on the family characteristics (see Table 4). Around one quarter of families were rated as having improved in terms of physical health, family functioning and coping but equally some situations had worsened, notably in terms of a risk of family breakdown (N=8: 19% of families).

Table 4: The number and percentage of families who were rated as having changed in last six months in the characteristics listed.

		Ratings			Total [^]
		Some improvement	Same	Worse	
Physical Health	Count	11	29	3	43
	%	26%	67%	7%	
Emotional well-being	Count	14	51	5	70
	%	20%	73%	7%	
Family functioning	Count	15	46	7	58
	%	26%	79%	12%	
Sibling wellbeing*	Count	7	27	4	38
	%	18%	71%	11%	
Risk family breakdown	Count	9	25	8	42
	%	21%	60%	19%	
Coping	Count	21	39	6	66
	%	32%	59%	9%	
Involvement with services	Count	13	9	1	23
	%	57%	39%	4%	
Co-operation with services	Count	15	10	2	27
	%	56%	37%	7%	

[^] The number of families for whom this had been noted as a problem

* $p < 0.05$ for differences in these behaviours across the types of services

Improved wellbeing of siblings was reported for a higher proportion of families using Short Breaks than for Intensive Support (30% v 10%) (Chi Sq 9.2: $p < 0.06$).

As Table 4 also shows, the majority of families had improved involvement and co-operation with the services. These improvements were significantly related to improvements in parental well-being.

There was a significant relationship between ratings of parental improvement and children’s improved behaviours (Chi Sq 18.4:p<0.001). As Figure 5 shows, a much higher number of parents were rated as having improved in terms of the well-being indicators when the behaviours of the child had improved.

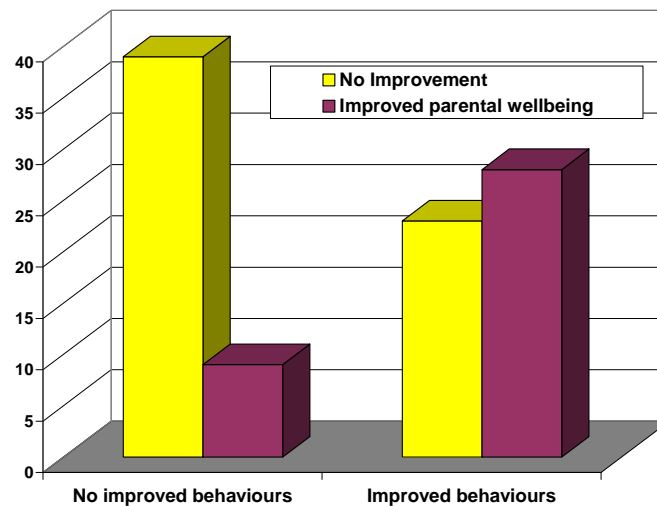


Figure 5: The number of parents showing improvements in their well-being by improvements in the child’s challenging behaviours.

Conclusions

Over the past six months sizeable proportions of the children were reported to have shown some improvements in their communication and personal care. Likewise around half the children have improved in terms of their stereotyped behaviours and aggression to other people. Children who had received Short Breaks tended to have improved behaviours, especially if they received a greater number of nights per annum. This was linked with improved ratings on parental well-being. For small proportions of children the risk of moving out of the family home had increased rather than decreased.

These figures may underestimate the amount of change that had occurred in children and families since they commenced the services. Ratings taken over a longer time period would better reflect this. But by contrast, they may over-estimate the change that families experience in that improvements may be realised more in the service settings than at home when there is no staff support.

The data for change would be stronger if ratings had been taken six months previously and then repeated prospectively rather than done retrospectively. Also more detailed measures may well have identified more discrete improvements in the children.

Further details about reported changes are contained in the accompanying reports⁷.

⁷ Report 3: The Short Break and Intensive Support Services provided by Action for Children in Cardiff, Edinburgh and Glasgow

Strand 6: Perceptions of Stake-holders

A further strand of information gathering, entailed individual interviews with the main stake-holders who were personally involved with a randomly selected sample of families. The aim was to gather rich qualitative data to illuminate their experiences of short breaks and intensive support services from which an analysis could be made of the dominant themes that typify their perceptions of these services.

Sample

From the database of past and present families who used the three services (N=123), a random selection was made of 17 families (six each in Edinburgh and Glasgow, and five in Cardiff.) For each chosen family, we aimed to interview the primary carer of the child or young person, their key-worker in the service and a representative from a partner or referral agency, such as social workers. In addition, we sought to obtain the views or reactions of the young people through a combination of interviews and observations (see Strand 7). In this way we would build up a picture of how the services were perceived for each chosen family by the various informants.

From the original selection of families, four parents declined to participate and replacements were selected. This was also an opportunity to check the characteristics of the sample against those of the population of users and on most indicators they were comparable.

However, not all participants were contactable in the time available and despite repeated attempts to speak with them. Nonetheless, the following individual interviews were completed; 48 in all.

- *Family members*: N=14 (11 mothers; 6 fathers).
- *Key-workers*: N=17.
- *Partners*: N=17 (mostly social workers but also psychologists and community nurses).

Method

A structured interview schedule was prepared in order to ensure that a comprehensive account was obtained from each group of informants in line with the overall aims of the review. Face-to-face interviews with family carers were conducted in a range of settings, including the family home and in a private room within the short break house. Likewise interviews with key-workers were conducted in the short break house or by telephone. All the informants from partner agencies were interviewed by telephone as this proved most convenient for them. Permission was given by most informants for the interviews to be audio-recorded and when this was not forthcoming in two instances, extensive notes were made during or immediately after the interview.

The interview recordings were transcribed verbatim and an interpretative phenomenological approach was taken to analysing the data (Smith, 2004). This aimed to identify the main themes that underpinned the experiences of the informants with respect to short break and intensive support service in which they had a personal involvement. A particular strength of this study is that it brought together the experiences of three different people all of whom had a common involvement with one chosen child and repeated this for three services in different locations.

The findings were validated in two ways: first by the team of researchers who worked independently in collecting the data, and second, by the three Steering Groups for each of the services who reviewed the findings independently as well as by the national Steering Group. The local groups consisted of all the main stake-holders with over 15

people in attendance. Through discussion they confirmed and elaborated on the main themes and explored the implications for future provision of this type.

The findings

In keeping with qualitative research methodologies, most of the data is in the form of quotations taken from the interviews arranged around the dominant themes that emerged when their responses were collated (see Figure 6). As the over-riding opinion of these services was very positive, they are represented by a gold star! For example, one father commented:

I think it's excellent. I could wish that he had respite more often but so does every other parent, I am sure. I feel the people are extremely hard working and dedicated and very pleasant. They give a very welcoming front when you go there. I really can't fault them. **Father**

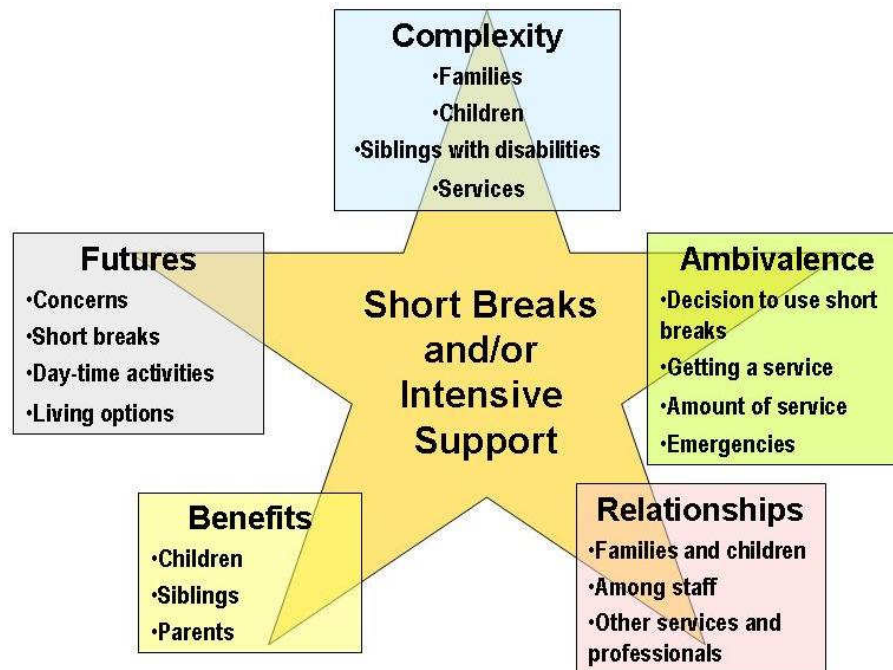


Figure 6: Main themes in stake-holders' experiences of short break and intensive support services

Likewise a social worker said:

Fantastic staff – I'm 16 years in social work and have worked with lots of agencies – they stand out as one of the best. Open to ideas, enthusiastic, good communication, nothing is a problem to them – very accommodating, flexible, listen and respond to what parents (and others) tell them, passionate in what they do. **Social Worker.**

There were five sub-themes that contributed to this positive evaluation. An accompanying report gives a full account of the findings so only the main themes are noted here⁸.

Theme 1: Complexity

Throughout the interviews, the complexities underlying the provision of services to this particular group of families and children were very apparent. These stem from family circumstances, the nature of the children's impairments and disabilities and the service

⁸ Report 6: Perceptions of Short Break and Intensive Support Services: The perspectives of stake-holders across three services.

packages that had been created to meet these needs. The provision of high quality services is especially commendable under these circumstances.

*Mum has obviously got a few issues herself regarding her mental health I think its burn out. She's always caring for a great aunt or her mother and obviously she has got another son with a disability in the house and from what she tells us, N can be a bit challenging. **Key-worker***

*N has fragile X syndrome and it affects his behaviour and he has learning disabilities as well. He needs care 24/7 cause he has no control over his urine or bowels. **Father***

*He's got a twin brother who is autistic as well ..., they both go to short breaks together mostly because mum's requested that. They are both demanding in very different ways so mum is kind of split, cause N2 wants to be going out going to the cinema, going to a restaurant while N1 only want to eats KFC in the car. **Key-worker***

It requires particular expertise coupled with experience and commitment to provide effective support services to families who have such complex needs and to do this amongst a complex package of service inputs from differing agencies. This complexity needs to be stressed so as to distinguish these more specialised services from other forms of family support services.

*He's got a very high package (from different agencies). It's difficult she (mum) doesn't know who is coming from one day to the next or where he's going or who he is going to be with and everybody is all different as well - everybody is different and all the staff from (names another service) haven't had the same training that we've had. They don't know how to manage his behaviour – I don't take anything away from them - they are doing the best job they can but it's not as much as N needs. **Key-worker***

Theme 2: Ambivalence

Somewhat surprisingly, families had an ambivalence about using short breaks. This showed in that it was others who prompted them to seek the service, in their hesitation to use it and in their views around the number of overnight breaks or hours of support that they received. It was apparent too in their perceptions around the benefits as the next section illustrates. Staff too expressed some ambivalence around the value of giving extra support in certain circumstances.

*It was really (mother names social worker) she suggested (Intensive Support) because not everybody would maybe want involved; you know people come to their house and whatever you know, so she suggested it and I thought about it and she put the referral through. **Mother***

*There's a sense in which I feel a failure for having to use the service. They have opened N to new experiences, going on bus trips and staff taking him to places he wouldn't ordinarily go to with us, as he would find them stressful. **Mother***

*I am happy with the hours I receive – it fits like a glove for me. I don't want any more hours and don't want to offload N on others. The level of service makes me appreciate what others may be missing. **Mother***

*Do you want the honest opinion? I think it's the people who shout the loudest get what they want and sometimes you have got young people with massive packages; we have another young person who has a massive package 6 days a week and it doesn't need to be that much, and we've got other people with no package. So the people who shout the loudest get more sessions. **Key-worker***

The impression from this theme is that short break and intensive support services require a careful judgment by parents, social workers and services as to when this service might be offered to families; the amount of support that is provided and how this is adjusted over time and in response to competing demands. It is a tribute to the expertise of

personnel involved with the provision in these three services that they succeed in doing this with apparently little complaint.

*I would say (the number of overnights) is right now. I don't think anymore would be beneficial. I was always wary of it being too high in a sense that N would be out of the family too much and it was important that it wasn't seen that he was being sent away, I thought that that would be very negative. **Key-worker***

Theme 3: Relationships

The third major theme that recurred throughout all the interviews was the centrality of relationships in creating an effective service. Foremost was the relationship between service staff and parents, mothers especially but also with the wider family. The relationships that the service has with other providers and professionals are also vital and distinguish these services from others. Overall, the services are held in high regard largely on the basis of the relationships they have forged and their style of working.

Various strategies are used by the services to build relationships with families.

*With N's mum, I know I have got to give her designated time for home visits and reviews. I have done home visits before and very often with us she just needs an offload and she needs somebody to listen to her. **Key-worker***

*They have a nice approach to families, non-judgemental and non-directive. They support families to identify the problem and give them support to think through what to do about it. If the parent works with them, then there are good outcomes. If not, then parents give up. **Social Worker***

*It was consistency of staff- it was me and another worker when he first started. We very rarely put other staff in, because you had to build up the relationship with N. He's very clever and he'll know what's expected and if someone came in and perhaps was too soft or too hard - do you know what I mean - it had to be just two of us at first. He responded to relationships and N had to trust you I think. **Key-worker***

It was evident from interviews with key-workers especially, that their relationships with the service was a key factor in building and sustaining the relationship they had with the children, families and other services. Being trusted with responsibilities, having opportunities for training and receiving ongoing support were all mentioned.

*I am a builder by trade .. I had been for 5 interviews and nobody wanted to know and the manager here said well we'll give you a chance and within a space of that year they more than gave me that chance. They have given me lots of responsibility which I knew I thrive on challenges. I have just done my SVQ and HNC they put me through that, they supported me through that, so I personally couldn't ask for more. **Key-worker***

*Obviously you are restricted with policy and procedures and stuff like that, but you are encouraged to do things you know. you are encouraged to network, you are encouraged to meet with other projects so you don't need to stay insular and you are encouraged to contact people as well that's the main thing I like. **Key-worker***

The services strive to integrate their work with that of the other services who are supporting the child and family. This involves a willingness to learn from one another and to actively share information.

*There was a point when (names other service) take young people out but they can't always manage their behaviours, perhaps because they don't have the psychology input, so what we do is we come in and do all the behaviour management plans with them the PECs, the TEACCH and all that kind of stuff, and then we pass the information on to their staff. **Key-worker***

Throughout the interviews the closeness and importance of personal relationships came through. This places many more demands on service managers and staff but the rewards are very evident in terms of the gains for the children and the young people especially as the following theme makes clear.

Theme 4: Benefits

All the informants were able to recount a range of benefits from using the services: for the child, the parents and for siblings. Although the services are often labelled as 'respite for carers', the interviews provided many more specific examples as to how the children have benefitted with the outcomes for parents being less tangible.

He's is a lot more sociable and tolerable of situations that he wouldn't have dreamt about coping with in the past. He is definitely a lot more relaxed child he just loves coming here.

Key-worker

We are toilet training N and that's still in progress, they do it at the short breaks house but we do that in the community as well. At the moment he wears pads but what we do is take them off him during sessions and toilet him. The hope is that he eventually learns to use the toilet and he is improving yes. **Key-worker**

We take him to different parks and take him on runs in the car we take him to the airport to see the planes we take him swimming, we try everything. **Key-worker**

The challenging behaviour in itself too, while its decreased over the years, it's only ever present at home. I have never even seen him get like angry here, whereas I have seen him at home and he is definitely different in how he responds to them and that to me is just historical; that is the way they have grown up as a family together and it's not something you can just change from different environments. **Key-worker**

N's more able to interact in social settings- not so stressed. He can attend clubs and is doing well at school. School has reduced the support they give N. The home environment is also easier. He's more able to behave like any other wee boy. **Social Worker**

Throughout the interviews the siblings of the child and young person were seen as major beneficiaries by parents as well as by key-workers. In this respect, the parents did not necessarily get a rest as they spent the time with their other children.

They have three other children and it's quite a busy household so taking N out into the community give them time to spend with their other children and do activities with them. When he is in the house it has to be safe and locked up to make it safe so it makes a big difference to the siblings just being able to go out and come in and do activities. **Key-worker**

The breaks were also seen as a benefit to parents but given the complexity of their lives and their own needs, the time away from caring was often filled with other demands.

The benefits I gain are uninterrupted sleep, the capacity to do my work as (I am) self-employed, taking my daughter to things on a one-to-one basis and doing practical things around the house such as washing. Also just getting to be on my own – I've taken to doing an hour's yoga. **Mother.**

What was amazing is mum took N and his brother on holiday on her own and that would never have happened before. **Key-worker**

The primary rationale for short break services has been in terms of the gains for parents and while they do benefit, as this data makes clear, it is the children and young people who are reported to benefit most. Perhaps this is more a feature of these services in that they have an explicit function to promote the children's well-being and social inclusion. But it is a reminder that assumptions about these services may need to be re-shaped in terms of how they are presented both to service commissioners and to prospective family users.

Theme 5: Future Planning

Concerns about future service provision often arose spontaneously in the interviews especially with families of young people approaching 18 or 19 years when the service would end. However this theme had been identified by the steering groups as one that needed to be explored particularly in terms of future living arrangements for the young people.

Parents were conscious of the major changes that they faced once their young person reached adulthood plus service staff were dubious if the same form of short break would be available.

*While they are children they are protected but then you know all of a sudden they're adults and not only are we as parents expected to put them out there but then there's all this change but not only of them being adults but their safety net almost is taken away and sometimes I worry that its going to be yanked away. Cause he's going to stop school and then this (short breaks) is going to be taken away from him and other clubs and things that he goes to that's going to get taken away and its almost as if one door is shutting and then another one. I haven't had any input yet from transition services so I don't really know what to expect and that's my worry. **Mother***

Families were eager for the existing style of services to continue.

*I wouldn't want N put in with like adults, I would prefer her to be in with kids maybe 18 to 25 no more. N has got a very, very young mind as well and putting her in with older people I don't think would be beneficial for her. I am willing to lose respite if that's the case I just wouldn't put her in there. **Mother***

*I would hope that by the time comes, Action for Children would be more established or even have a centre of their own taking them possibly from 19 to 25 or into further adulthood. **Mother***

For some young people it seemed that some form of residential provision would be needed as the family were unlikely to cope.

*Unfortunately for N, it will end up in a residential placement because mum has said that, but she just can't let him go yet. I mean it's really hard for her cause she doesn't want him to go but she's being quite honest and I think ultimately he will. Well last year when they found him a placement, mum was like - No, I want to hang on for another year - so it's been another year so I don't know. N is now 16/17 now I think. **Key-worker***

Informants had a clear idea of the type of living arrangements they felt would suit the young adults. Indeed, the use of short breaks was seen by some as a preparation for moving from the family home.

*My wife and I always said when we first started to get respite that it was preparing N for the future because we know that someday N is going to have to go into residential care when we get older and can't manage him, so we thought that him going into respite care is preparing him for that - being away from home. **Father***

*I would like her to be settled somewhere where she can have the experience that she's had at (Action for Children) being able now to experience the theatre, swimming, ice skating now other things like cooking, independence. I would just like her to be settled somewhere where she is going to be cared for. **Mother***

The tone of the interviews tended to change when the topic of future provision arose. The positive, upbeat comments around current experiences gave way to more sombre reflection about an uncertain future in which wishfulness, even a sense of helplessness typified the remarks of all the various stake-holders. Creating a clearer pathway for families through the transition to adulthood will require concerted efforts from all partners and thus far, in all three locations, this is still evolving.

Improvements to Services

All informants were asked during the interviews to name any improvements to the services. Many struggled to find anything to report and when they did, they often qualified it by stating it was not a major issue or they appreciated that the issue was outside the control of the service. Nonetheless a number of themes were evident in their responses which are summarised here.

The most common complaint from some parents was the short notice they were given of changes to the dates of the breaks or when staff would come to the home.

*They have phoned me at the last minute when she has been due to go in about a swap and I know that kids can come in, in an emergency, and that was a bit stressful because we were set to do something. **Mother***

*I stopped it (outreach) because it wasn't doing any good to him as there was shortages of staff so I decided to stop that and just do the respite. Because sometimes they were coming out and sometimes they weren't. **Mother***

Longer notice for dates was another request as was more consultation with parents.

*I think that NCH (now Action for Children) should listen more to the parent's side than just going in with their feet first and giving you dates. **Mother***

Key-workers noted a number of issues that they felt to be addressed within their services and they along with some parents mentioned certain improvements to the facilities.

*A bigger building, you have got 5 kids in that house over there it's really quite intense and challenging because they are in each others faces all the time it's not big enough. But seemingly there is plans for an extension so we will wait and see how long that takes. **Key-worker***

One theme that arose in interviews with partners was that of improved communication between the services and themselves. Clarity around the goals of the service was also mentioned.

*I think there should be some clearer indication of timescales for how long the service lasts. When do we know we've done the job? When do we handover to another provider? That's what I would say about trying to improve it probably. **Social Worker.***

Conclusions

Arguably the interviews challenged some myths around the provision of short break services to families and the way they are currently delivered. For example:

- Although often termed 'respite' services that are aimed at giving the parents a break, which they do, this review suggests that it is the children and young people (including siblings) who are perceived to gain more from the services than do the parents.
- Parents can be ambivalent about accepting short breaks and/or support services although they are often persuaded of their value when they start to use them.
- Parents seem reconciled to accepting the quantum of service they receive and are understanding of the needs of others and constraints under which the services operate.
- Having multiple agencies involved in the provision of various forms of family support services, adds further complexity to an already complex situation. The rationale for doing this is not immediately apparent although this fell outside the scope of this review.
- The provision of short breaks and intensive support primarily assists families in the present and it may not remove the need for the young person to move away from the

family home in future years. However it could mean that lower levels of support are needed if the young person is able to do more for themselves and if their behaviours are more manageable.

- Although the children were reported by service personnel to exhibit fewer challenging behaviours, this did not seem to carry-over into the home context. The complexity of family circumstances could be one explanation but also a more explicit focus on parent's management styles at home may be necessary from the three intensive support services.
- Our informants spoke about the range of activities that the young people enjoyed in community settings but there was sparse mention of social contacts with non-disabled persons. Again the complex needs of the children presents major hurdles to doing this. Moreover the friendships built up by children through staying on a break together do not seem to be encouraged outside of the service.
- The transition to adult services presents major challenges in replicating similar standard of provision. New models of personalised support services may be required.

These and other issues will be taken up in the final section of the report.

Strand 7: The views of the young people and their social inclusion

Given the complexity of the children and young people it has been especially challenging to obtain their views on the services they had received. However it was important to provide them with an opportunity of doing so and an accessible information sheet was prepared for them and their families (see Appendix 3). It was decided though not to approach children who had left the service.

In addition information was obtained from parents and key-workers as to the activities they did outside of the home.

1. Young people's views

Of the 12 families currently receiving services who were selected for Strand 6 of the review, only five young people were judged by key-workers as likely to give meaningful responses to questions. Also this would be best done in the company of staff whom they knew and in settings with which they were familiar, such as the short break house. But the constraint then was the availability of interviewers when the children were booked in for a stay.

An alternative strategy was then used to boost the number of child informants in that key-workers identified other young people who would be attending the house at the same time as the target child and sought permission from their parents for them to be interviewed. To date information has been obtained from 11 children although this includes interviews conducted solely by key-workers. (However similar responses were found to those conducted by the interviewers as key-workers were also present then too.)

In addition observations have been undertaken by the interviewers when seven children were attending the short break house as a means of gauging their experience and one was in receipt of intensive support. However key-workers felt that it was not appropriate to do this for other young people receiving only Intensive Support services as the presence of another person might cause them unnecessary anxiety.

Two dominant themes

Two main themes are apparent in the young people's responses: namely their likes and their dislikes. First they do seem to enjoy coming for short breaks and to have intensive support from home. Primarily this is because of the activities they experience out in the community. They also value the relationships they have with staff and often look to them for re-assurance and comfort. The second theme of dislikes included missing their families, being away from their own home and possessions.

Activities

Table 5 lists the range of activities that the young people said they enjoyed when they came to the short breaks or were out with staff. In fact, 'going out' was mentioned by nearly all the young people who were interviewed which implies that these activities meant more to them than staying in the house, no matter how well it was equipped and furnished.

The things that people also liked were:

'relaxing'; 'having people to talk to; getting a cuddle when upset; having own space; nice place to stay; being on holiday; meeting new friends; learning new things; feeling safe in bed; having a big person to call on if felt unsafe; having friend stay at the same time; having TV in room; bring own DVDs; phoning home; having a double bed to sleep in

Table 5: Activities enjoyed by the young people

At the house		Going out	
Baking	Playing pool	Swimming	Loudon Castle
Reading books	Art	Beach	Walks
Football-garden	Washing up	Parks	McDonalds
Playing outside	Bath	Cinema	Shops
Bicycles	Soft play	Bowling	Drives in car
Computer – play station	Cooking, Ironing	Fairgrounds	

It was evident from the observations that staff related well and sensitively to the young people often making physical contact with lots of non-verbal, encouraging communication. The staff were observed using various other communication aids although it was not always clear as to the children's level of understanding of them.

Some were happy to be left to do their own thing as shown by this extract from observation notes:

(Name staff) used the PECS (Picture Exchange Communication) book to prompt a move to having time in the garden where N enjoyed a long game crumbling up dandelion heads and releasing clouds of seeds in the air. During this time he smiled and laughed to himself though he didn't really respond to our efforts to engage in the activity with him.

On other occasions the children were observed lying on couches in a relaxed manner but ignoring the television which was on at the time.

Dislikes

The young people mentioned a range of things they did not like about coming to the short breaks. 'Missing their family' or *being away from home* were things nearly all mentioned, particularly their mum, dad, a favoured sibling or their pet dog! Among the things that different individuals noted were:

Upset by the dark at night-time; staying for only two nights instead of five; too many people in the house; other people annoying me; not being able to use the computer at the house; having to go to bed at 9 o'clock when staff tell you.

However these were outweighed by many positive reports which parents also confirmed. Indeed one young person liked it so much she wanted to get a job at the short break house!

Concluding comments

The views expressed by these young people concur with those reported in previous studies which provides some validation as to the dislikes in particular recounted by the young people in the services (see literature review: p.13). However these do not appear to outweigh the benefits that the young people gain from attending and the services often actively try to minimize the things that detract from the children's enjoyment of the service. The person-centred nature of the service is a major plus in this regard.

2. Social Inclusion

An aim of the services is to promote the social inclusion of the children and young people. This term has various meanings but at its most basic it can refer to their physical presence in community settings. Given the challenging behaviours of these children and for some, their dislike of being in noisy and crowded settings, there are increased risks

for families and staff in taking these children outside of the family home of the short break house.

In order to assess the type and extent of the opportunities they had to avail of community-based activities, parents and key workers were asked during the individual interviews to identify from a checklist those activities that the young person had done and those they would like to see them do in the future (see Table 6).

Table 6: The percentage of children participation in community activities as reported by key-workers (N=15) and family carers (N=12).

Activities	Does Key-worker	Does Parent	Like to do Key-worker	Like to do Parent
Out for a walk	100%	100%	n/a	n/a
Visits to Park/Beach/ Outdoor events and places	93%	92%	7%	0%
Shopping centres/supermarkets	87%	67%	6%	17%
Swimming Pool, Water Parks	87%	67%	13%	8%
Going to Café / restaurant/ pub	80%	92%	7%	8%
Go on bus, train journey	80%	83%	27%	0%
Cinema, theatre, concerts, museums	67%	58%	13%	25%
Taking part in <i>indoor</i> sports/activities with other children /young people – gym, karate, bowling, darts, snooker	60%	42%	13%	17%
Dance/drama/ art classes	46%	50%	40%	0%
Party/Celebration at home	40%	33%	26%	8%
Holiday/weekend break/day trips	33%	75%	47%	8%
Visiting relatives/friends/neighbours at their house	33%	67%	20%	0%
Taking part in <i>outdoor</i> sports/activities with other children/young people: e.g. football, cricket, tennis.	33%	17%	20%	8%
Having a friend to visit at home.	13%	25%	20%	50%
Visiting a friend at his/her house	13%	25%	20%	17%
Church, religious celebrations	13%	25%	20%	0%
Sleeping over at a friend's house	13%	8%	13%	17%
Having a friend to sleep-over	7%	8%	20%	33%
Watching sports events: e.g. football, rugby, ice-hockey	7%	8%	27%	0%
Discos/clubbing	7%	0%	27%	0%

The table shows the percentage of children who had taken part in each activity as reported by the key-workers for 15 children and likewise by parents of 12 children (NB the same children are included in the ratings by key-workers). The raters were also

asked to identify activities that the children might like to do if they had not done so. These percentages are in the last two columns.

This information has to be treated with some caution. It may not be representative of all the children who use the services and certainly some activities are more appropriate for young people of certain ages. Also this information does not give an indication of the frequency with which the children engage in the activity or the duration of them. Hence when children come to the short break house, it is likely that only a selection of activities take place on any one visit. Thus the information may overstate the extent of the children's regular participation in community activities.

That said, Table 6 summarises the proportions of children who participated in the various activities listed. It is noticeable that the ones in which most of the children participate are activities that do not require participation with other people. By contrast less than half are involved in activities that do require interactions with others such as indoor sports, dance or parties. Even fewer children have more personal contacts, such as visiting friends at home.

The pattern of responding across activities by key-workers and parents is broadly similar although key-workers seem to engage higher proportions of children in certain activities such as going shopping or swimming than do parents. This confirms other reports that the children are provided extra opportunities through using the services. By contrast parents are more likely to take children on day trips or holiday breaks and to visit relatives. Other evidence suggests that their being able to do this may follow on from their positive experiences of the services.

Regarding activities that the young people might like to try that they had not done, those most frequently identified by key-workers were day-trips/holiday breaks, dance/drama or art classes; watching outdoor sports events and discos. The two main ones for parents were having a friend visit and sleeping over. They chose none of the activities identified by key-workers.

Conclusions

This information confirms the opportunities provided by the services for the young people to participate in a wide range of community pursuits; although this varies according to the young people's characteristics and wishes. This is no mean achievement given the severity of certain children's behaviours and the need for two staff to accompany them backed up by detailed risk assessments and careful management plans. Moreover this exercise confirmed the wide range of activities in which the children could take part and provides a framework for staff and parents alike in extending their experiences of community living.

Physical presence though needs to extend to social interaction with others in order for richer forms of social inclusion to develop. This aspect seems less well developed and for some of the very good reasons noted above. However it precluded undertaking the consultations with community personnel that had been envisaged in planning the evaluation. The Local Steering Groups reported that staff and the young people had very limited amounts of regular, personal contact with the same individuals as they went shopping, to cafes and so on. Moreover the likelihood was low of community informants knowing them by name and the service they were from. Finally the effort involved in distributing questionnaires would exceed the likelihood of getting a reasonable number of responses. Nonetheless there could be value in services documenting through case-studies how they and the families have facilitated the young people's social inclusion in youth activities and in the promotion of friendships.

Strand 8: The costs of providing the services across the three locations

It fell outside the scope and competence of this evaluation to undertake a thorough analysis of costs involved in delivering these services although work is ongoing to do this within Action for Children. However it is apparent that these services are at the higher end of the costs reported in past studies and summarised in the literature review⁹.

The reasons for the higher costs are readily apparent from this report given the model of service that is provided (see Strand 2) and the characteristics of the children and families (see Strand 4). In summary, they are:

- The level of staffing required to cover the risk that the children present to themselves and others. This can mean two staff to one child when on outings and sometimes when they attend the short break home.
- The need for at least one, sometimes two waking staff when the children are on breaks.
- The individualised planning and service delivery with its associated need for detailed record keeping and staff hand-over meetings.
- The integrated model of support that is provided to families over and above direct contact with the children.
- The recruitment of qualified staff with the talents and personal qualities required for this work.
- The amount of training provided to the staff on an annual basis including refresher training.
- The level of management support required to co-ordinate the various elements of the service and to maintain close communication with partners.
- Transporting the children from schools to short break house is an additional charge plus travel costs of staff to/from family home for Intensive Support plus travel to community activities.

Moreover the costs have to be seen in context of the provision of other specialist forms of service delivery. For example the estimated cost of children in looked after secure accommodation is on average £471 per day and similarly the costs of maintaining young people with learning disabilities who have severely challenging behaviours is on average £475 per day. The cost of inpatient acute mental health hospital care is around £600 per day.

Comparable figures for outreach services for children and young people are not readily available. The ongoing work on this issue would be a valuable addition to our knowledge about the costs of specialised service costs.

⁹ Report 1: Supporting Families with Disabled Young People whose Behaviour is Severely Challenging: A Review of Literature. p. 21 onwards

Conclusions and Recommendations

The seven key lessons to emerge from the evaluation of the services can be summarised as follows.

- The services are specialist provision for selected children and families with complex needs. The staff have particular expertise and experience. The services are aimed at the most needy persons.
- Strong partnerships are maintained with commissioners and other service providers to provide co-ordinated packages of support to families. They cannot function as 'stand-alone' services.
- The amount of service provided to families is carefully matched to their needs and can be increased and decreased. This not only ensures cost-efficiency but it is in the interests too of the children and families.
- Short breaks and intensive support help children become more competent and reduce their challenging behaviours. The expertise and experience of staff means they are well suited to advise and train others, such as parents or staff in other services.
- Parents benefit when their personal needs are identified and trusted relationships are forged. Merely providing a break is insufficient to help reduce the stresses they experience. Parents also gain personally from improvements in their children.
- The young people have increased opportunities for participating in community activities which is a major achievement given the children's behaviours and reputation but their social inclusion remains limited.
- No clear pathways exist for the transition to adult services. Major improvements are needed in the way adult services provide for these young people and their families.

In this final section, the implications of these lessons are explored and recommendations provided for how the services can further develop.

Recommendations

At the outset of this study a mother from a local steering group complimented the services she received by stating:

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.

It is in that spirit of 'working out of the box' that these recommendations are made. Five main areas emerge from the evaluation around which conclusions and recommendations can be drawn. These emerged through discussion of the study findings with the three local steering groups during September (over 20 stakeholders attended including parents, front-line staff, managers and various partnering professionals) and with the national Steering Group. Their insights were invaluable in identifying the realities facing families and services and hence the issues that require ongoing attention if the services are to fully realise the ambitions they hold for themselves and the families they serve.



Specialist, selective provision

The provision in these three services is beyond what might be typically thought of as 'short breaks'. They are better considered as specialist services and this is evident in a number of ways: the intricate service model that has evolved; the qualifications and training provided to staff, the complexity of the children in the service and the individual assessment and planning that underpins the work of the staff both in the home and in community settings. This specialist provision has taken time to evolve and has required the support of various partnering agencies. Hence they place particular demands on the leadership of these services as they balance the competing demands of the commissioners, the needs of the families and the young people, the deployment of staff and the expectations of senior managers in Action for Children. This requires constant organisational learning and flexibility; attributes which these services need to continue to nurture.

Not surprisingly these specialist services may cost more than other short break services although comparable data can be difficult to ascertain. However this report has clearly demonstrated the added value that these services provide but in times of austerity, clear justification for the costs will be needed.

Nonetheless a 'specialist badge' brings with it certain implications; foremost of which is the selective nature of the service. It is important that the eligibility criteria for the services are made explicit along with the goals they aim to achieve for families. There is a residual problem of families having entered the services some years back under less stringent criteria and who would be no longer eligible if they were presented to the referring panel. In time, these families will move through the services but if financial stringencies were to be applied, it could be that these families might have to be referred to other providers so that they can be replaced with those with greater needs.

A linked issue is the criteria used to allocate the amount of support hours/nights provided to families and how this is adjusted over the time during which they access the service. In the main, the amount of service allocated to each family is usually set by the commissioners. Nevertheless a review of the allocation (i.e. for more or less time) is more likely to be instigated by the Services. The extent to which services proactively re-assess family needs may require closer scrutiny especially as the data obtained in the evaluation suggests that an increased number of nights – rather than a decrease - is associated with families who have used the Short Break services for longer periods of time. This suggests that families appear to have a continuing need for Short Breaks as the child grows older rather than the service decreasing their support as the coping skills of family carers improve.

However a comparable increase does not appear to happen with Intensive Support hours and these services largely work towards a planned withdrawal of the support. It may be that similar arrangements will be required for *specialist* Short Break provision with the aim of moving the family on to other short break providers over an agreed time period which would vary according to family need. Of course such arrangements will only work if there are other less specialist, short break services available albeit at a lower cost. In all three areas this is the case at present. Moreover it could include referrals to other Action for Children services.

Yet this demarcation of functions across different 'tiers' of Short Break services is not clear in current arrangements. As the evaluation found, multiple agencies are involved in the provision of various forms of family support services to certain families, all of which adds further complexity to an already complex situation. It would seem more efficient for one agency to provide specialist input for a designated time period with a view to them transferring the family to other lower tier services as the need for specialist support recedes. Inherent in this proposal is a commitment from the specialist service to train

and guide the staff in the receiving organisation and indeed this is already happening successfully in Cardiff.

Specialist services are founded around specialist personnel. In the main this comes from front-line support staff whose job descriptions, person specification and remuneration need to reflect the specialist nature of the work they undertake. They are more than social care staff. The organisation's commitment to their ongoing training and development is impressive and will need to be maintained even though this aspect is often the first to suffer from cutbacks.

But the frontline staff need support from knowledgeable practitioners and in this respect having a clinical psychologist as part of the staff team - as happens in the Edinburgh service - seems an particularly effective model given the behavioural challenges of the children and young people. This overcomes the availability problems when the services are dependent on 'visiting' or advisory staff whose own workloads may preclude them from prioritising support for the short break services.

Recommendation

The services need to debate and reflect on the extent to which they portray themselves as specialist providers and seek that acknowledgement from commissioners and partners.

Family support

The services are not just for children with particular needs but they strive to support the child within their family. To that end, the services - including staff working in the Short Breaks - have forged close contacts with families and are seen by parents as a major form of emotional and practical support for them. In some ways this is understandable in that these staff come closer than any other professional as to what it is like to live 24 hours with their son or daughter.

But against this, the services are ostensibly provided as a substitute to parental care in that the children and young people avail of short breaks or take part in activities within the community away from their families. It is not surprising then to find that parents express some ambivalence about availing of short breaks; expressing feelings of guilt or of failure. This requires sensitive handling if their morale and confidence in their parenting abilities is to be maintained and strengthened, alongside an appreciation that coming to terms with the child's disability is a recurring process. Careful judgments are required as to when families are ready to accept and hence benefit from the Short Break or Intensive Support services on offer. But from the outset, the service needs to become a trusted, reliable ally for parents. This finds expression in various ways but one in particular is the access to an emergency place should it be required at short notice. Although the need for such placements did not arise often, it is essential that services maintain this option.

A trusted relationship also makes parents accepting of changes in their short break arrangements that may be necessary if the service is to accommodate others with arguably greater needs. Even so, parents would like to have as much notice as possible about available dates; an issue that was mentioned most often as a service improvement. Also when there are two or more children with a disability in the family, it is crucial that the breaks are co-ordinated otherwise the parents do not get the break they need or want.

The information gathered in the review suggests that the services were commissioned when there was a particular risk to the integrity of the family such as a member of the family moving out or a fulltime residential placement is sought for the young person. However in only a small portion of families did this risk recede; for most it remained

unchanged but for a proportion of families the risks were deemed to have increased during the past six months of using the services. Hence it is rather simplistic to think that the provision of short breaks and intensive support will prevent children moving into full-time care. Rather a complex set of parameters may need to be balanced. As some informants noted, the provision of too many breaks can loosen children's ties with their families but equally if the quantum of services is spread too thinly across families, then it may be insufficient to help families cope and could trigger removal from the family.

Also the strategy of removing the child for short periods to give family members a break – especially when the child has major behaviour problems - may need to be complemented by additional approaches such as training and counselling for parents. For example, the evidence of improved behaviours when children are with the services does not seem to be mirrored in parental reports of their behaviours at home. In part this may be due to the complexity of their home circumstances compounded by the inadequacy of their housing but a necessary debate within Intensive Support services especially, is the extent to which the services provide more explicit support to families through the provision of groups for parents and for siblings. These could be used to impart knowledge and skills as well as a forum for discussion and reflection.

A linked issue is staff working with children in the family home so that parents can be guided in the use of management strategies that the service has found effective. Both these types of developments would represent an expansion of these services into more specialised work based on the needs of families and it is one for which the Cardiff and Edinburgh services are actively preparing and which Glasgow is successfully doing.

Recommendations

The services should pro-actively re-assess the quantum of service provided to children and families in line with their changing needs.

A wider range of training and personal development opportunities should be developed for families.

Outcomes for children and families

A topical debate within health and social services is the impact they have on the recipients; in this instance, the outcomes they achieve for the young people and families who use Short Breaks and Intensive Support. During the evaluation we aimed to evaluate this in various ways through rating scales, self reports and the opinions of significant personnel. Ironically an over-arching conclusion is that although such services are often termed as 'respite' for family carers, the evidence suggests it is the children and young people (including siblings) who are perceived to gain more from the services than do the parents. This manifests itself in improved behaviours and increased competence in communication and self-care skills. In addition the young people have access to a range of activities and leisure pursuits they would otherwise be denied.

This growth of competence is especially pertinent when looking to the future in that these young people will require less supports when or if they move away from their families than they might otherwise have done. Indeed some parents cited these experiences as a primary reason for why they requested short breaks. Thus there is scope for the services to lay claim to the role of supporting the children to become more competent. With this expertise and experience they would also be in a position to advise other services with whom the child is in contact, such as schools and leisure/befriending services and already there was some acknowledgement that this is happening despite the perception of others that all the staff did was 'look after' children.

The outcomes for family carers were harder to discern. It appears that few parents took a rest during the break from caring, if anything by their own admission they became hyperactive doing things that they were unable to do when the young person was at

home! Others mentioned how little time they still had as a couple and through time this could drive them apart. These accounts may go some way to explaining why past reviews of short breaks services have found little evidence of reduced stress or better health among carers. One approach would be to offer more formal opportunities for mothers especially to learn about relaxation and taking care of their physical and emotional well-being. Another was to provide opportunities for informal socialising such as family play days and coffee-n-chat sessions as the Glasgow service has done. These have the bonus of parent-to-parent supports developing and reducing the social isolation many families experience.

A number of cautions have to be noted though when it comes to the assessment of outcomes. Many of the children are receiving packages of support services and efforts are made to ensure that these are co-ordinated across the various provider agencies. This makes it harder to establish the distinctive contribution that each discrete service makes to the overall improvements observed in families and children. Hence it can be difficult to attribute changes solely to the Short Break and/or Intensive Support services.

The time frame over which changes are monitored is another important consideration; should it be every six months, annually or longer? Moreover it is possible that the changes are cumulative over time and by focusing only on the most recent period, as was the case in this study, this would under-estimate the changes that have occurred in the children and families since joining the services. Ongoing monitoring of children and families by the services would provide data around this issue and especially as to why more improvements in the children tended to be reported for those using Short Breaks rather than Intensive Support. Hence the services should review the IT systems used to record the children's level of functioning and behavioural problems, and also pertinent indicators of family wellbeing. These records could then be used on an ongoing basis to provide reports of outcomes for the children and families.

Finally some informants expressed concerns about the organisation being too outcome focused. If this focus is centrally driven, then the individuality of children and families may get lost; attention would be deflected from the processes of creating the outcomes and hence risking losing the personal relationships on which the services are built.

Recommendation

The services should develop IT systems that more readily identify the outcomes for children, parents and siblings.

Social Inclusion

The young people and families who use the Short Break and Intensive Support services experience a great deal of social exclusion even though they live in community settings with their parents. The same happens for many children with disabilities but is even more accentuated with those who have challenging behaviours and limited communication. Not surprisingly, families may be reluctant to risk bringing their sons or daughters into public places but this can extend into family visits or having visitors come to the home. The social isolation may compound other family difficulties.

It is encouraging therefore to find that the Short Break and Intensive Support service have a major emphasis on providing opportunities for the young people to engage in a range of activities in community settings which means they are at least physically present within society. Often this requires careful assessment of risks and the planning of management strategies coupled with the provision of two staff to one young person if required. Although these procedures underpinning community participation feature prominently in the intensive Support – Outreach service, it is an aspect of Short Breaks that may be under-appreciated by the commissioners. However these opportunities are

rated highly by the young people and although it would be cheaper to maintain them solely in the home setting, the quality of the short break experience for them personally would be much reduced.

There was sparse mention of social contacts with non-disabled persons during these activities. Again the complex needs of the children presents major hurdles to doing this but perhaps the service personnel could give more thought to this aspect of social inclusion. The advantages are around the young people having role models and peer expectations as a further means of managing behaviours. It is also an opportunity for young people to observe and understand their peers who are different. Examples could include supporting the child's participation in sympathetic youth clubs and sporting groups.

An interim step towards this form of social inclusion, is for a young person to share activities with another (compatible) person during Outreach activities rather than a single child with one or two staff as usually happens in the Intensive Support service. This would have financial advantages as well if two children were supported by two staff. This is being piloted in Cardiff.

Likewise the Short Break services endeavour to build friendships among the young people by having the same group staying together at the same time. The extra effort required to manage these bookings could pay-off in other ways, if the young people were also encouraged to maintain their contact between stays: e.g. by visiting one another at home despite the geographical distances that may separate them. In the longer term too they would have companions with whom they might live in supported accommodation.

In the longer term, a radical re-appraisal might be made of the way short breaks are provided. During the evaluation different informants spoke of the possibility of a staff member accompanying the family when they went on holiday to support the young person with special needs but within the context of activities that the families wanted to do. This has the added advantage of ensuring the child's inclusion within the family but also offered periods of separation so that parents and other siblings had a break on their own. The wider use of self-directed support could mean this option and others like them, might appeal to families who are reluctant to use the services as they are presently delivered. Nonetheless for children with complex needs it would be vital that the staff involved in such innovative schemes are well trained and experienced with access to suitable back-up.

Recommendation

The services should increase the opportunities for building social relationships among the children and young people and with others in the community.

Transition to adult services

The Short Break and Intensive Support services end when the children are 18 years of age. The needs of the children and families should then be met through adult health and social services. Although staff from these services were not directly involved in the evaluation there was widespread agreement among other informants as to how ill-prepared adult services are to meet to the needs of these children and families. It was even suggested by some partners that the amount of services families receive during the older teenage years should be scaled back to get them used to having no provision in adulthood! Parents and staff spoke of their concerns for the future and both parties spent a great deal of effort in seeking suitable alternative placements for the young person with the word 'fighting' featuring often.

Equally there was recognition that mixing older teenagers with younger children was not ideal and services tended to manage this by age-grouping the children when they came

to the short break house. It was also suggested that having self-contained 'wings' in a reconfigured house is another way of encouraging friendship groupings: an option the Glasgow service would like to pursue as their building lends itself to this.

Nearly all informants recognised that the young people and families had a continuing need for a similar style of service to that which they had experienced with Action for Service. A favoured option was for the organisation to develop a similar Short Break service for older teenagers and young adults (16 to 25 years). Although this has the potential for creating two transition points rather than the one at present, the advantages outweighed the present arrangements post-18 years. These were: the organisation has the expertise and experience to provide a high quality service; the young people would continue to make progress during this phase of their lives (rather than regress through lack of service) and these new short break services could act as a transition into the supported living services that many of these young people will require in their adult years or when their families are no longer able or available to care for them. The chances of these new services taking place in the current financial climate would be enhanced if they were built around self-directed funding opportunities. Indeed there seems little reasons other than financial, as to why Outreach/Intensive Support services should not continue to be provided at least up to 25 years of age if the family has a need for them.

Another model mentioned by some informants was for the Intensive Support to be extended to the young adults who may live in a self-contained part of the family home. This would bridge into the 'floating support' provided under the Supporting People funding initiatives or funded through self-directed payments.

However any of these developments would require the support of commissioners. Yet the lack of contact, let alone influence that children's services have with their adult colleagues was depressingly poor. People spoke of the chasm that existed between the two service systems in both health and social services. At its most basic, adult services seemed unaware of the increased number of children with complex needs who are surviving into adulthood and who are being sustained in community services.

Some partners spoke of the need for children's services to more assertively share the innovative and effective service models they have evolved so that planners have a vision of what might be possible. If this was done alongside the advocacy of parents and young people there might be some hope of politicians and commissioners listening. Several parents spoke of their determination that their child would leave home when they turned 19 and had the services under notice of this even though it was some years away. Others pinned their hopes on legislative changes to define entitlements and the need for major policy shifts to break the 'care culture' that pervades adult social care provision.

Recommendation

Action for Children, in association with their partners, should prepare plans for comparable services to meet the needs of 16-25 year olds and their families.

Final words

The value of any evaluation is not so much in what it uncovers but in the actions that it triggers among those who have the greatest stake within the services. So in a sense this is but the end of the beginning. In due course, Action for Children locally and nationally would be advised to create an Action Plan to take forward some of the issues and recommendations identified in this report. It goes without saying that this needs to be done using the same partnership approaches that have typified the evolution of these services, allied to a capacity to work outside of the box.

Appendix 1: Action for Children disability services¹⁰

Action for Children has become a major provider of services to disabled children, in partnership with local authorities, PCTs and Health Boards. Currently we run 71 projects providing specialist services for disabled children; this is in addition to over 9,000 disabled children accessing our inclusive children's services. A significant number of children using Action for Children's current services have severe learning disabilities and associated challenging behaviour, complex health needs or life-limiting illnesses.

Our specialist disability services include domiciliary care, residential short breaks (which accounts for over half our commissioned services for disabled children), residential care and schools, Children's Centres, transition support, key working, advocacy, family based short breaks, specialist and inclusive play and leisure activities. Whether community based, family based or residential, all our services are tailored to meet the aspirations of individual children and young people.

Action for Children Intensive Support Short Break Services

Within our range of services we have three intensive support short break services these are Gilmerton Road, Edinburgh; Cardiff Breakthrough; and Stoneside Short Breaks, Glasgow. These services have formed and are funded in differing ways however their common denominator is that they support disabled young people and their families to stay together. They also keep the young people included in their communities by for example, supporting them to use universal local facilities.

Gilmerton Road has been operational for 11 years, funded by NHS Lothian and the 4 unitary authorities in Lothian. Referrals are processed through a multi-agency panel who use a 'vulnerability tool' to prioritise those most in need. The service offers assessment and behaviour support planning for disabled children and young people with severe and enduring challenging behaviour and has a dedicated half time clinical psychologist and the services of a CAMHS Consultant Psychiatrist. This is integrated with service provision by a dedicated staff team who support children to access residential short break services and provide outreach support to enable children to enjoy leisure, play and sports activities in the community.

The key aims of the project are:

- To provide a comprehensive and flexible support service for the children and their families, as responsive as possible to their needs.
- To value the child or young person with learning disabilities and challenging behaviour and maximize their potential.
- To work in partnership with the child and their families, to consider their views and wishes, and operate a policy of openness and involvement with the child or young person and their family.
- To encourage children and families to fully utilise local community resources and to provide support to enable them to do so.
- To work closely with the Project Partners, and with schools, Health services and other service providers for children and young people with learning disabilities and their families.
- The service will develop individual medical, service and behavioural support plans which will assist each child and young person to develop his/her potential, taking into account their emotional, spiritual, intellectual and physical needs, Parents will be consulted fully about plans and will agree their content.
- The service and Action for Children are committed to the protection and safeguarding of children and young people.

Stoneside Short Break Service has run an intensive family support service for disabled children whose behaviour is challenging, alongside a residential short break service since 1999. Referrals for children aged 3-16 years are made through a multi-agency resource screening group and most children are on the Autistic Spectrum. Two full time staff work with the child and family in their home or school and work closely with the learning disability CAMH's team to support the practical implementation of behaviour support strategies. They also model and support parents in boundary setting. On occasions this is crisis intervention to prevent a child

¹⁰ Information supplied by Action for Children

becoming accommodated, for example, where families are at high risk of breakdown due to the intensity, frequency and severity of challenging behaviour. The staff also work directly with young people to help them learn anger management strategies or develop age appropriate life skills such as independent travel.

The service aims to provide opportunities for:

- Short breaks for children/young people up to the age of 18 who have arrange of disabilities and challenging behaviour.
- Intensive Family Support for families with a child (or children) whose behaviour presents a significant challenge to the family, education and social work.
- Holistic care planning developed in consultation with the child/young person, their family and other agencies involved on a regular basis.
- The child/young person to be less dependent on their families and develop new friendships and social experiences.
- Children and young people to maximize their potential in a range of areas including self-help skills, confidence-building etc.
- Parents/carers to develop and sustain skills to manage their son/daughter's behaviour within and outwith the home environment.
- Families to see their son/daughter in a positive light and see the potential in their relationships/

Cardiff Breakthrough has run since 1997 is co-located with a residential short break service and provides intensive support to access community based play, sport and leisure activities for a small group of very challenging young people aged 7-17 years at risk of exclusion from other services for disabled children. The young people are likely to have extensive needs including being on the autistic spectrum with severe learning disabilities. Access is for 6 months followed by supported transition to other service provider's and seeks to deliver specific objectives such as reducing the risk of social exclusion; supporting skills development and safer ways of expressing need; supporting children and families to have a better quality of life. It is supported by a Clinical Psychologist.

The project aims to increase the inclusion of children with severe learning disabilities between 8-18 years, who present with severely challenging behaviour into ordinary and specialist services in their local communities, whilst embracing and supporting the capacity of families to care for the child and sustain the family group, within the city of Cardiff.

The objectives of the project are:

- To reduce the exclusion of children and young people who show severely challenging behaviour in junction with other agencies.
- To support children and young people to develop and enhance their skills in natural settings.
- To support children and young people to minimise the impact of their inappropriate behaviour and encourage positive behaviours.
- To help prevent children who display severely challenging behaviour, going to live in an out-of-county residential placement.
- To enable parent/carers and other family members to have a break from their caring responsibilities in order to maintain and enhance children and young people's position within their families.
- To involve parents/carers, and where appropriate children and young people, in the planning and review of services provided.
- To ensure all staff has the skills and knowledge required to carry out their duties to a high standard.
- To ensure all aspects of service delivery and employment are anti-discriminatory and value diversity.

Appendix 2: Lessons for future evaluations

At the final meeting, the Steering Groups were asked to identify the features of the evaluation that they would particularly commend and any changes they would make to the process with the benefit of hindsight. They noted:

- ☑ The process created an ownership for the evaluation and an understanding of the process among all the participants.
- ☑ A holistic approach was adopted – different needs and perceptions were covered.
- ☑ It challenged preconceived ideas.
- ☑ People enjoyed their participation and for many it was the first time they had been able to share their experiences across different stake-holders.
- ☑ The involvement of parents in the groups was most beneficial and this should be maintained by the services as an aid to planning and review of services.
- ☑ Interviewers were prepared to go to the family home rather than expect parents to come to their offices which often happens with other professionals.
- ☑ It was good that front-line staff had a voice in the Groups – often they can be overlooked in higher level activities like these.
- ☑ The process helped staff morale and reinforced the benefits of the services.
- ☑ It felt like real partnership working and partners were interested in the findings.
- ☑ The groups might have benefited from the involvement of other professionals such as CAMHs personnel.
- ☑ There was shared decision-making about the interpretation and implication of findings.
- ☑ Took away any fears about what an ‘evaluation’ meant - should make other services more willing to participate in evaluations.
- ☑ Information was accessible to managers in a way they did not have before.
- ☑ It provides a legacy of collaborative working that can built upon.
- ☑ Managers and staff felt empowered to undertake their own internal reviews.
- ☑ Existing IT systems were not suited to the information required – they need to be reshaped.
- ☑ Monies were available to managers to cover extra costs involved in information gathering and making arrangements for meetings and interviews.
- ☑ The person leading the evaluation needs to be open, adaptable and encouraging.

Appendix 3: Young people's consent form



Hello. My name is Roy.

I would like to talk to you.

It's about Stoneside. This is what I want you to tell me.

What do you like about



Stoneside?

Anything you do not



like about Stoneside?

How have the people at Stoneside helped



you?

Are there new things you want to try
Stoneside?



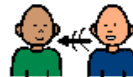
when you come to

All you tell me



is private.

If I think you might not be safe, I will have to



tell others.



You can stop at any time.

I will write



down what people tell me.



Here's my phone number if you want to contact me
028 90 36 88 89

Thank you for your help