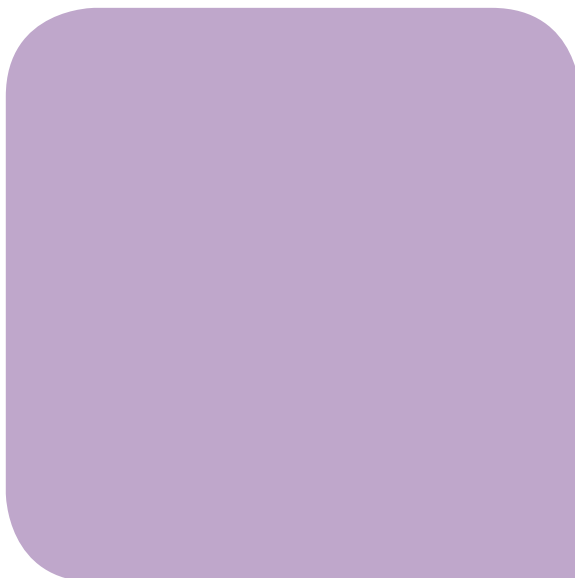
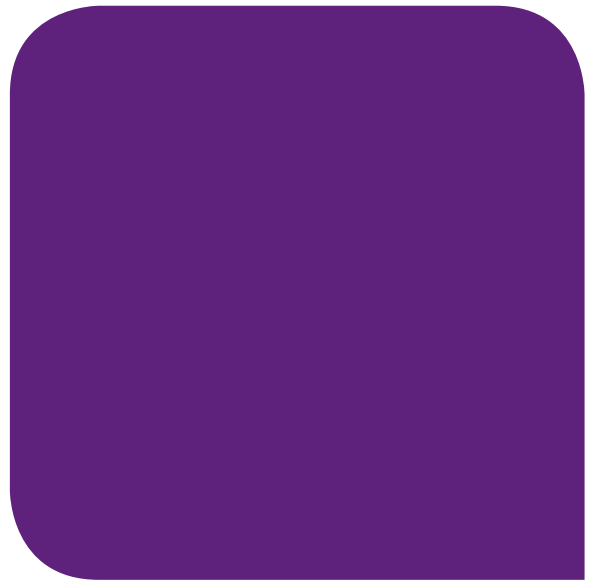


Having a break: good practice in short breaks for families with children who have complex health needs and disabilities



Having a break: good practice in short breaks for families with children who have complex health needs and disabilities

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Key messages

- Disabled children want to lead ordinary lives. Relationships with their families and friends are very important to them. They do not always want to have breaks without their families and away from home.
- Parents of disabled children want practical, flexible help and a break from the physical and emotional demands of caring for their child. They often wish that their relationship with their disabled child could be more 'ordinary' and they did not always have to perform caring or nursing roles.
- Traditionally, services providing short breaks have focused on residential care solely for the disabled child. New types of short break are better at meeting the needs of the whole family. They are flexible and offer many different kinds of support.
- The new models of short breaks have the following positive characteristics:
 - they are flexible and responsive to the whole family's needs
 - they can be based at home or in the community
 - they ensure continuity of care
 - they offer stimulating and educational activities
 - they are family-centred
 - they support parents
 - they are distinct from healthcare services.
- There are many reasons for developing these new kinds of service, including:
 - Parents' expectations have changed. They now want services to offer more rewarding experiences for their children that will further their child's development. Parents are also more willing to ask for the help they need.
 - There is high demand for these new kinds of service because they are much better at meeting families' needs.
 - The new commissioning arrangements for health and social care offer many more opportunities for funding the development of imaginative and innovative practice.
- More research is needed to establish the financial costs and benefits of these new models of service, but experience to date suggests they result in better quality service provision without incurring additional costs.

Introduction

In December 2007 SCIE published 'Necessary stuff. The social care needs of children with complex health care needs and their families' (Knowledge Review 18). This outlined the evidence base for working with this group of children and their families. One of the key areas identified for further development was 'short breaks', a service which parents often request. It is a service that also needs to address several complex issues.

- Disabled children want to lead ordinary lives and relationships with their families and friends are very important to them. They do not always want to have breaks away from home without their families close by.
- Parents want practical, flexible help and may express the desire for a 'breather' from the physical and emotional demands of caring for their child. At the same time, they often express the wish that relationships between themselves and their disabled child could be more 'ordinary' and they did not always have to perform caring, nursing and other roles.

SCIE has carried out further research to gather information about innovative and imaginative practice in providing short breaks. The project involved:

- contacting a wide range of stakeholders with a request for examples of innovative practice, which they also distributed to their networks
- semi-structured telephone interviews and follow-up with respondents
- collection and collation of innovative practice examples.

This project was supported by The Council for Disabled Children at the National Children's Bureau and the Aiming High Implementation Group. These groups also highlighted the importance of this topic, particularly as a **new duty** on local authorities to provide short breaks for disabled children was introduced in March 2008.

The organisations which contributed to this project were:

Mid Essex Primary Care Trust (PCT)
The Hamlet Centre Trust, Norwich
West Hertfordshire PCT
Nascot Lawn, Watford
Norfolk County Council
Rainbow Trust Children's Charity, Leatherhead
Shooting Star Children's Hospice Hampton, Middlesex
South East Essex PCT
Southern Health & Social Services Board (SHSSB), Northern Ireland

SCIE would like to thank all those in the above organisations who provided the information about their work, and also Christine Lenehan, Director, Council for Disabled Children, for her support and advice.

Who is this resource for?

This resource guide has been written for commissioners and service providers responsible for services for children with complex health care needs and their families. It has drawn upon the experience of organisations that have broken new ground in the area of short breaks for families such as these. By sharing these examples of good practice, SCIE hopes to facilitate the spread of more innovative and family-centered services.

If you would like further information about any of the services described in this resource guide, please contact Mary Sainsbury at SCIE (mary.sainsbury@scie.org.uk).

What kinds of innovative short breaks are provided for families?

Short breaks are often thought about in terms of providing children with residential care, but in fact they include a much wider range of services. A short break can range from a few hours to several days. Parents and siblings may want to stay with the child, or the family may wish to take a break at home, particularly as this allows the child to continue seeing friends and stay in familiar surroundings. Providing such a wide range of services requires much greater flexibility than has traditionally been the case.

These are some of the different types of short break identified through this project.

Under Fives groups

These offer a two-hour break to parents while their children take part in a variety of activities adapted to suit their individual needs. (The Hamlet Centre Trust, Norwich)

Saturday play schemes

These are play schemes, much appreciated by parents, which offer, for example, crèche facilities or play groups over the long summer break. These take place in community leisure facilities and include a mix of children. Parents are able to use the facilities at reduced rates. (Orana Community Service, Northern Ireland)

“Saturday play schemes are very popular. Families can come to the town centre and do their shopping and family activities while their disabled child is being cared for.”

Staff member, The Hamlet Centre Trust

Summer holiday play schemes

Separate schemes are run for children aged 3–8 years, 9–12 years and 13–18 years in the school summer holidays, and are suitable for children with a wide range of disabilities. Activities are planned to be age-appropriate and flexible enough to meet the needs of the children attending each day. A minibus takes groups of up to ten children out every day to take part in community activities. (The Hamlet Centre Trust, Norwich)

School holiday play schemes for children with complex health needs

Specialist groups providing one-to-one support for children who find it more difficult to use play facilities because they require nursing care. Twelve children attend each day on 24 days per year for a six-hour session. (The Hamlet Centre Trust, Norwich)

Youth clubs

Weekly clubs for children and young people aged 8–13 and 13–18 on weekday evenings in term time. Staff ratios are high enough to ensure that those with high care needs can be fully included in activities. Children contribute to the planning of the programme. (The Hamlet Centre Trust, Norwich)

'Transitions' summer holiday club

A service for young people who are making the transition to adulthood. Supported by four members of staff, they choose how they want to spend the day: swimming, bowling, picnics in the park, trips to the cinema, pubs and restaurants, and so on. This allows them to take part in activities similar to those of their peers, but with appropriate support to ensure both their safety and the peace of mind of their parents/carers. (The Hamlet Centre Trust, Norwich)

Home-based care

A nursing service in the child's home provided by a qualified trained nurse or trained carer. This can include day care, evenings and weekends or a night-sitting service (Mid and South East Essex PCTs. West Hertfordshire PCT; Norfolk PCT/County Council).

Good practice example

South East Essex PCT has two full-time nursery nurses (National Nursery Examination Board trained) providing a caring and support service. They have additional training to provide specialist paediatric care and can take sole charge of the children. There is also medical back-up, although this is rarely needed. Parents can choose either to go out by themselves or to have help with the child while at a function such as a party or swimming gala. This can help the child and parents to take part in activities with siblings. Due to the small size of the team and high demand, the sessions are currently restricted to three hours. However, two sessions can be offered back-to-back, giving a maximum of six hours.

Home-based palliative care

Community teams offer outreach care providing home-based nursing services for children with life-limiting and terminal conditions. (Norfolk PCT; Mid Essex PCT; SHSSB, Northern Ireland)

Home-based support worker

Support workers go into the family home and undertake a wide range of tasks, from washing windows and helping with the shopping to taking a sibling out to get a break from home. Staff are not medically trained and do not provide nursing care. (Rainbow Trust, Leatherhead; Crossroads, Norfolk).

"Offering practical help is a safe way for families to let in people to help and build up confidence with a support worker."

Staff member, Rainbow Trust

Residential units

These units provide holidays for children on their own or with their families. Typically they offer both indoor and outdoor activities as well as having staff to provide nursing care and support as needed. (Rainbow Trust, Leatherhead; Norfolk County Council)

Good practice example

The Rainbow Trust Children's Charity based in Leatherhead provides breaks for families in two residential units. They have numerous facilities, including indoor pools. Staff are on hand to carry out all household tasks and offer support to the family. Homes also have 24-hour phone lines to staff support should families require it.

What are the positive characteristics of the new models of short break services?

Traditional provision of short breaks takes the form of residential care solely for the disabled child. By way of contrast, the new models have the following characteristics.

They are flexible and responsive to the whole family's needs

Different kinds of service are provided at a time and place that suits the whole family, such as on Saturdays. Staff are also very flexible in what they do.

"The nurse can accompany the whole family on an outing, for example to a wedding, so the parents can relax, spend time with all their children and be freed up from nursing duties."

Staff member, South East Essex PCT

"We are flexible as we can be ... especially for families in crisis. We have to provide support and services when they are needed, which is not always planned for. Families need to be able to cancel or book at short notice ... It is about supporting families to say what they need rather than telling them what's on offer."

Staff member, Rainbow Trust

"It's not easy to cope and we take one day at a time. A short break makes it a bit easier ... It is difficult to plan as we don't know what is going to happen to my child."

Parent

"I enjoyed being able to give all my attention to my daughter as the staff saw to our other needs."

Parent

"It was nice spending quality time as a family all together – something we haven't done for a while. We all arrived tired and stressed and we are leaving relaxed and full of energy."

Parent

Good practice example

Nascot Lawn, Watford is very flexible about the support they offer. For example, they can provide 'short notice care' (not emergency) which allows a family to decide they need a break in the day at very short notice and phone up and ask for time. This sometimes involves asking other families to agree to a swap. Most

will try to be flexible, as they recognise it may be their family who needs to be accommodated next time.

The siblings of children with complex health needs are also offered support and care themselves.

“Our staff often work with siblings who are struggling at school or home. There have been several cases where a sibling has been reintroduced to school and their behaviour has improved considerably ... when at the beginning it was thought a referral to mental health service might be necessary.”

Staff member, Rainbow Trust

“I was worried about my son aged four because he was really affected by his brother’s death. The staff at the residential unit brought him out of his shell and let him have some fun time.”

Parent

“The short break service allows us to have ‘me’ time and helps us to feel normal and allows family activities with our other children.”

Parent

Good practice example

The Southern Health & Social Services Board (SHSSB) in Northern Ireland has developed young carers’ services for all siblings. Families have the option to fast-track this service, avoiding the stigma of going through social services.

They are based at home or in the community

Home-based care is preferred by many families, although some parents find this does not give them a complete break from the daily routine. A flexible approach is required to satisfy both the children’s and the parents’ wishes.

By taking part in activities in the local community disabled children are helped to feel they are living ‘ordinary lives’.

Good practice example

The Government’s *Disabled Children’s Access to Childcare* pilot projects are developing networks of ‘specialist childminders’. These will make it easier for parents to find flexible childcare that meets their needs (including overnight and home care) and help disabled children to participate in play and leisure activities in their own communities.

They ensure continuity of care

Services that provide continuity of care over time are highly valued by disabled children and their families. It allows them to build good relationships with staff, develop trust and feel confident that their needs are recognised and understood.

“We ensure continuity of care wherever possible by working in partnership with the local community health trust and maintaining strong links with local special schools and other professionals working with the children.”

Staff member, The Hamlet Centre Trust

“The same staff move between the hospice and people’s homes, providing care based on knowledge of the individual children.”

Staff member, Mid Essex PCT

Good practice example

The Rainbow Trust Children’s Charity typically provides support to families with sick children for two or three years. Some support lasts a lot longer, up to 10 years. Families can opt out of receiving support at any time but can also opt back in again if they need to. They can even choose to continue using the services after their child has died. They can receive home visits from a family support worker or take a break at one of the residential units. Many families do come back to the home for short breaks, as they feel it is a place where they can grieve and gain support from staff who knew their child.

They offer stimulating and educational activities

Services that provide a stimulating and rewarding experience for the children ensure that the children benefit as much from the short break as their parents. If parents know their child is going to have fun, they are also better able to relax and enjoy themselves.

“Getting a break at the same time as my child is having great fun is obviously the best combination, giving the rest of her family a far more relaxed time ... The days that Lucy is invited to the Centre are unequivocally fun for all of us. Lucy is thoroughly enjoying herself, and therefore we feel no guilt at doing exactly the same ... It’s not the longest session in the world, but Lucy loves it and is really happy and worn out at the end of the day, and her siblings are able to tell her about the fun that they have had and share their tales of their day. What more could you ask for?”

Parent

Good practice example

The Hamlet Centre Trust has a toy library with specialist toys and activities for disabled children. There is also a sensory room and a playroom where children on the play schemes can play with the toys. The library is unusual in being staffed five days a week. The library workers provide advice to parents and demonstrate suitable toys and equipment. They also keep up to date with new developments, including sensory/switch toys. Parents can make suggestions for new purchases within the funds available.

They are family-centred

Care plans and activities are developed with input from the families using the services. This ensures the support they receive will meet their particular needs. Initially this requires carrying out a detailed needs assessment.

“We carry out a detailed assessment of each family to see how best services can be provided. It’s a very well developed tool and allows us to provide more personalised services.”

Staff member, Mid Essex PCT

Each child is also offered as much choice and control as possible over how they spend their time and who they spend their time with.

“We have arranged for two friends to have a short break together, explaining to them that it is their sleepover. This idea greatly appealed to the two girls who are both wheelchair users. The families could not have done this as their houses cannot accommodate two chairs.”

Staff member, Nascot Lawn

They support parents

Staff recognise that parents can find it difficult to leave their child and so provide the necessary reassurance.

“Parents are positively encouraged to go out and to have good time; they know the nurses can take charge.”

Staff member, South East Essex PCT

“I went to the park without my child for the first time and I was really worried, but the staff understood that.”

Parent

“The staff give me confidence that I can leave my child with them. This takes time to achieve.”

Parent

Through receipt of specialist advice during the short breaks, parents are also encouraged to provide more advanced care at home.

“In all our services we want to provide a stimulating educational environment for the child ... We work on positioning, gross and fine motor activities, communication and play. We help parents to stimulate their child, play appropriately with them and to continue doing this at home. This gives parents increased confidence and higher morale.”

Staff member, Mid Essex PCT

“We’ve had no stays in the hospital since having this support as we feel better equipped at home now – no rushing off to the hospital in the middle of the night.”
Parent

“It has also given us the confidence to spend a night or two away from home despite having to use specialist equipment.”

Parent

They are distinct from healthcare services

Disabled children and their families want to avoid feeling like they are 'going into hospital' while on a short break. As far as possible they want to retain a sense of normal life. However, at the same time many children do need specialist nursing care. Some organisations have managed to 'de-medicalise' their services, for example by creating new types of post.

“While some care is still provided by nurses, we have also created a hybrid post by training up care assistants (NVQ level 3 and 4) to provide the complex care that the children need. As well as being cost effective, families like it. The staff relate well to all the family and quickly develop a rapport with them ... perhaps they seem less 'professional' and 'medical'.”

Staff member, SHSSB

“The nursery nurse can administer medication and do the feeding, they have the knowledge to do all the jobs that I do, it’s very rare to find a care package that does that.”

Parent

Why develop innovative models of short breaks?

Parents' expectations of services have changed

In recent years, an increased awareness of human rights and equal opportunities has led parents of disabled children to expect more of health and social services. They now ask for their child to be provided with a more rewarding and stimulating experience, one that will further their child's development and maximise their life chances.

At the same time, a stronger focus on consumer rights has encouraged parents to become more demanding. In the past, families did not have many expectations of services and regarded their child as their sole responsibility. Nowadays, families are much more willing to ask for the help they need.

"Parents now tell us what they want. We don't tell them what we can provide."

Staff member, Mid Essex PCT

The new service models are requested by parents and better meet their needs

The majority of the types of short breaks described in this resource have been developed in direct response to requests from parents. There is a huge demand for these kinds of services.

"An evaluation day was organised several years ago and the Saturday play scheme came out of that. The Saturday scheme has grown out of the holiday scheme because parents requested it."

Staff member, The Hamlet Centre Trust

"Our best value review in 2001 said that parents want these services. We can always justify service developments because we have built in consultation and evaluation with families."

Staff member, Norfolk County Council

There is also evidence that these services are better at meeting families' needs. Many of the service providers described in this resource are seeking funding to expand their services and ensure more equitable access.

"Our home-based palliative care for terminally ill children was externally evaluated, which led to a decision to continue funding when the lottery grant ran out. This was a tremendous boost for the team. Now there is no limit on how long the service can be offered for and we work with the family to work out what will be most useful."

Staff member, Mid Essex PCT

“Our Saturday scheme is very popular and the commissioners are considering extending the scheme, with new money available nationally, for example Aiming High, because at present parents can only access the service once a month.”

Staff member, The Hamlet Centre Trust

New commissioning arrangements encourage innovation

The new commissioning arrangements offer much greater flexibility for commissioners. This will soon enable them to commission more imaginative and innovative services.

“It’s a question of commissioners getting to know what’s needed ... in future commissioners may want to use resources differently or initiate new services. This is not happening just yet, because the commissioning/provider split is still quite new.”

Staff member, Mid Essex PCT

“There is a new commissioning world which we are getting into step with.”

Staff member, Norfolk County Council

Adapting to these changes will require new ways of thinking and further engagement of families in the commissioning process.

“Commissioners need to be creative and it is more than thinking outside of a box, it is not seeing there being a box at all.”

Staff member, Rainbow Trust

“We have stakeholders included in the commissioning process and on the commissioning group. It’s these stakeholders, including parents, who often tell us what to commission – and what not to!”

Staff member, SHSSB

What are the financial costs and benefits?

There is currently little evidence available as to the financial costs and benefits of developing these new types of short break. Further research will be required. However, based on the experience of commissioners and service providers to date, it seems these services do offer better value for money.

“Home-based care is relatively expensive because it includes unsocial hours, but it is more cost-effective than residential care. It is often better value.”

Staff member, Norfolk County Council

“Home-based nursing probably works out cheaper because there are no capital costs.”

Staff member, South East Essex PCT

One provider has reduced costs by training nursery nurses to provide home-based care:

“The service costs less than residential care and less than using trained nurses. The estimated cost is £38 per three-hour session including on-costs.”

Staff member, South East Essex PCT

Providing breaks for families also seems to help to prevent many hospital admissions, thus making a saving for the NHS.

“Children are being admitted to hospital when they don’t need to be and for longer than they need to be. Giving families a break saves inpatient resources.”

Staff member, South East Essex PCT

Overall the new models seem to offer a better quality service without incurring additional costs.

“We are providing more services for the same amount of money. We haven’t had any increase in funding but we are doing things differently.”

Staff member, SHSSB

Developing short break services in the future

Many of the service providers and commissioners interviewed for this project had ideas and wish lists for improving and developing the services they can offer. These included:

- providing nursing care to accompany families on holiday, to enable the whole family to have a break together
- increasing the flexibility of funding arrangements to enable families to receive free care earlier on, not just at crisis points – this would help prevent the need for emergency care at a later date
- greater flexibility of funding arrangements to support joint activities for disabled children and their siblings – for example, combining PCT and local authority budgets to support family days out
- homework clubs for the siblings of disabled children
- under-fives groups for children with complex health needs, providing one-to-one support and access to nursing care.

Contributing organisations

Mid Essex Primary Care Trust

The Hamlet Centre Trust, Norwich

West Hertfordshire Primary Care Trust

Nascot Lawn, Watford

Norfolk County Council

Rainbow Trust Children's Charity, Leatherhead

Shooting Star Children's Hospice Hampton Middlesex

South East Essex Primary Care Trust

Southern Health & Social Services Board (SHSSB), Northern Ireland (NI)

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