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A GUIDE TO SHORT BREAKS

Supporting family carers and people with learning disabilities to have short breaks that work for them

Written by Paradigm on behalf of the Valuing People Support Team

12th June 2007

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VALUING PEOPLE
Support Team

ACKNOWLEDGEMENTS

The Valuing People Support Team commissioned Paradigm to write this Short Breaks Guide. The primary authors of this document are Julia Fitzpatrick and Alicia Wood, who conducted the research and interviews and wrote the paper. Peter Kinsella edited the paper.

We are very grateful to the assistance from Sue Carmichael and Cally Ward of the Valuing People Support Team for their support, advice and direction. We are particularly indebted to our colleagues in Mencap for sharing so freely their findings, ideas and experiences from their own extensive short breaks work.

Many people gave us their views, ideas and stories. Without them, a guide such as this could not be brought to life - thank you.

Image used courtesy of Say It Works (www.sayitworks.co.uk)

EASY READ SUMMARY

What's inside?

This is a brief guide to ways for family carers and adults with learning disabilities to have short breaks. It suggests ideas for what needs to be in place to develop good short breaks and to help people to access these.

It is written mainly for Learning Disability Partnership Boards but we hope other people will find it useful too.

Inside you will find information on:

- Short breaks - what are they?
 - What makes a good short break.
 - Finding out what people want and making changes.
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- A menu of short breaks options
 - Residential breaks
 - Family based breaks (e.g. Adult Placement Schemes)
 - Home based breaks, including increased care packages into the person's own home so that the carer can go away and overnight support to enable families to get sleep
 - Community, social and leisure breaks
 - Holiday breaks
 - Self directed breaks
 - Emergency back up breaks.
 - Essential ingredients - what you can do to make it happen.



Key messages

Short breaks help family carers to carry on caring. They help people with learning disabilities to get better lives. So money spent on good quality, regular short breaks is a good investment. But many people are not getting the short breaks they need.



Learning Disability Partnership Boards and Local Authorities need to know what is currently provided in their area and if it meets needs of people with learning difficulties and family carers.



They need to find out what people need and want as short breaks, involving families and people with disabilities in this work in any research and reviews.



Local Authorities need to develop a menu of short breaks options in order to meet the range of needs that will exist in most areas. Whilst residential short breaks can be innovative and of good quality, they do not suit everyone.



There are lots of different ways short breaks can be provided. It is important that families and people with learning disabilities lead the decision and have a choice about what will suit their needs best. There are different ways that Local Authorities can give people more choice and control over their short breaks.



Families, people with learning disabilities and staff should have up to date, accessible information about the short breaks options available, locally and elsewhere. There are lots of ways this can be done.



It is important that family carers have quick and easy access to assessment, and that there are clear and understandable systems for working out the minimum level of short breaks people can expect. This guide suggests different ways of doing this.



NHS and Social Services' short breaks services do not have to be separate. Joint Commissioning and other joint working can result in a wider range of services, accessible to more people including people with complex needs.



Children's services and adult services need to work together so that everything works well for young people and their families during transition.



Families and people with learning disabilities are clear about what they value for short breaks and these ingredients should be included as service requirements.



Money from different places can help in extending short breaks options so everyone who is eligible can get a break that suits them.



Short breaks can be made a development priority, with strong leadership responsible for delivering results.



1. INTRODUCTION

It is estimated that 60% of adults with learning disabilities live with their families and get most of their support and care from family members. Short breaks help to support family carers and help people living with their families to get better lives. This is why Valuing People says it is important to support carers and why the White Paper 'Our Health, Our Care, Our Say' directs organisations to provide better prevention services, earlier intervention and more support for people with long-term support needs and their family carers.

“With the right kind of short breaks, families will cope and will continue to support and care.” Mencap, Breaking Point 2006

Research has shown that people are not getting either the quality or the amount of short breaks they need. Many Learning Disability Partnership Boards and Local Authorities have found that they need to completely review their strategy and approach for offering and providing short breaks because what they provide does not meet people's individual needs. It can be rather old-fashioned, costly and sometimes poor quality. It may not be available often enough to meet people's needs. Many areas are already working out better ways to give people choice and control so they can get the short breaks they need. Others need to take steps to commission good services based on a good knowledge of particular needs in their localities.

This is a brief guide to ways for family carers and adults with learning disabilities to have short breaks. It identifies the features of these services that are highly valued by the people who use them and make a real difference to their lives. The guide suggests ideas for what needs to be in place to develop good short breaks and to help people to access these.

The information and ideas in this guide come from a wide range of sources:

- Meetings with a large number of people and families who use short break services in Ealing, Liverpool and West Sussex.
- Choice Forum (www.choiceforum.org) postings and follow up discussions.
- Questionnaires about short breaks filled in by families, providers & Commissioners from different areas.
- Talking with Partnership Boards, Providers and Commissioners to find out how they are making progress.
- Looking at short break services that people told us were good.

Although written primarily for Learning Disability Partnership Boards, we hope it will also be useful for family carers, service Commissioners and providers who want to develop ways of supporting families and people with learning disabilities to get more and better short breaks.

You can get information about the legislation affecting this subject and a summary of literature and research in a paper prepared by Norah Fry Research Centre from the Valuing People website, www.valuingpeople.gov.uk .

At age 26, Barry lived with his parents Geena and Robert and attended a day centre. The demands on Geena meant she was unable to sleep and her already poor health was

suffering. It was 1991 and a new type of short breaks service had been set up in Merseyside. Barry was one of the first people to be nominated to Natural Breaks and it provided breaks on one week day evening, one Sunday a month and a weekend break every six weeks. Geena recalls that these breaks were “heaven - people don’t realise the stress I was under”.

Since then, Barry’s breaks and support have evolved to respond to his changing circumstances and individual needs. His father passed away, his mother’s health continues to deteriorate and Barry had a PEG (Percutaneous Endoscopic Gastrostomy) tube fitted. Natural Breaks trained its staff so that Barry could continue to enjoy a full day of support within his community. Later his day centre was unable to provide the support he needed, so Barry now has support from Natural Breaks for five days and seven evenings a week. Whilst supporting Barry, this also benefits Geena, a lone isolated carer. Geena talks about the trust and relationships that have developed from the short breaks: “all Barry’s different stages - people have seen him through that with me”. Geena is now thinking about Barry’s support when she dies, and hoping that what started out as a short breaks service, can be the service that supports her son to stay in his own home and community.

2. WHAT IS A SHORT BREAK?

“The best short break gives a break to the carer AND gives a break to the person who needs support and care. The best short breaks benefit everyone.”

A good short break is responsive to unique family, individual and cultural circumstances, is regular and reliable, frequent enough and long enough, and enjoyable and meaningful for the person with a learning disability.

It is:

- for all family carers to get a complete break from the routine of caring, so combating isolation, stress, crisis and breakdown - *“to feel energised and able to go on”*.
- to help a whole family or community to keep including and caring for the person with a learning disability.
- for people with learning disabilities to get an enjoyable break from their families, with real opportunities and choices to try new experiences, make friends and learn new skills - *“it’s for learning skills and independence, taking risks, meeting new friends, you can find yourself and develop your identity”*.

Getting the right kind of break, at the right time, is a big priority for families. This is confirmed in most research carried out by Local Authorities and for Mencap’s Breaking Point reports (2003 and 2006). The Government and Local Authorities know that they have a duty to support carers with their demanding role: the right short breaks help carers to carry on supporting and caring and to maintain good health; and they help people with disabilities to maintain and develop skills, relationships and connections in the community. The lack of adequate short breaks can lead to a later need for more intensive and costly support over a longer time. Investment in good short breaks is cost effective and pays dividends in the future.

Families and people with learning disabilities are all different, and they want to be able to choose the type of break that suits them. They want a range of options to be available. Some people want a weekly break of a few hours - to go shopping, to take part in an activity, to sleep; some prefer a night or a day out; others need a longer break. Most people need different types of breaks at different times in order to cope.

3 SHORTS BREAKS - A RECIPE FOR SUCCESS

WHAT DO PEOPLE WANT?

Family members and people with learning disabilities may differ in their ideas about what makes a good break. However it is possible, with imagination and good collaborative working to offer breaks that satisfy both sets of demands and dreams.

Here are some of the factors which people said make short breaks work for them:

- The Local Authority has a good knowledge of current services and the extent to which these meet the needs of the people in their area.

- Accessible and timely information is available and provided.
- It is quick and easy to access a service.
- Breaks are regular, frequent and long enough.
- A range of options is offered which meets identified local needs.
- People can 'mix and match' different options, at different times, for different reasons.
- Services are flexible and responsive.
- Staff, individuals and families are matched so that enabling, supportive and trusting relationships can develop.
- Family carers and people with disabilities are involved in and able to influence changes and developments at different levels.
- Person Centred Planning is used to help identify what will work best for the person.

Croydon's Learning Disability Partnership Board asked its Social Services Department to research what carers and people with learning disabilities wanted from short breaks. They used money from the LDDF (Learning Disability Development Fund) for this.

The research started with getting family carers and people with learning disabilities to say what questions needed to be asked. They said that everything should be turned upside down by thinking how short breaks money could be used in a different way. They came up with new ideas, and common sense ideas:

- Holidays
- Home based breaks
- Help to have a break together as a family
- 'Session' breaks in the morning, afternoon or evening
- Extended opening hours for services already in place, such as day centres
- Using ordinary community places and services and asking them to cater for people with learning disabilities.

People wanted flexibility and choice - they wanted to be able to 'pick and mix' from a range of options. Work has started to make this possible:

- Compiling information on holiday breaks
- Commissioning a 'session break' service to provide regular short breaks for one person or a small group
- Commissioning good support providers that are able to offer more than 'care', and use the short break to support the person to have a fuller life and activities which do not rely solely on the family carers.

Contact: Lizabeth Williams, lizabeth.Williams@croyden.gov.uk, 020 8726 6000

FINDING OUT WHAT PEOPLE WANT AND MAKING CHANGES

Local Authorities need to take steps which ensure that change is pursued for positive reasons in response to identified needs. The experience of Barnsley Metropolitan Borough Council (page 29) also illustrates the importance of involving people, at locality and individual levels, in developing a transparent and fair approach to short breaks. Learning Disability Partnership Boards can ask these questions:

- Does your Local Authority have a clear picture of what provision you have now and what it costs?
- Do you know, and how do you know, what people need and want to meet their needs, to what extent these are being met and what the gaps are?
- Have you established ways of involving and listening to people who use services, their families and carers and those who have not been able to access these? It is important to involve people right from the beginning of work to review and improve services.
- Have you looked into additional sources of funding that can help in extending short break options? Page 28 has some details.

The rest of this guide is set out as a 'menu' of options that if achieved in any one area means that more people are likely to get the breaks they need.

4 THE SHORTS BREAK MENU

One size does not fit all. At different times people need different sorts of short breaks to suit their needs. Every area will benefit from having a range of options to offer family carers and the person they support and care for, and a range of ways in which this can be organised and paid for. Many areas are now providing alternatives to the traditional fixed 'unit' model for short breaks. These help to reach more people, including those who have not been well served by existing systems: people living in rural areas, people from black and minority ethnic groups, people with significant healthcare needs, people with autism and young people in transition.

The person with a learning disability may also be a family carer - looking after a parent or sibling or partner. Some older carers will need their own support - perhaps they are having some memory loss or becoming confused, perhaps they are getting physically frail. Both may need short breaks provided by people who are sensitive to their circumstances.

Where a family has more than one disabled person in the family, each person may need respite from the other, and need and want different things from the short break. It is important to balance the needs of everyone involved as individuals and a wide range of flexible options will make this easier to achieve.

The menu that follows includes:

- Residential breaks
- Family based breaks (e.g. Adult Placement Schemes)
- Home based breaks, including increased care packages into the person's own home so that the carer can go away and overnight support to enable families to get sleep

- Community, social and leisure breaks
- Holiday breaks
- Self directed breaks
- Emergency back up breaks
- The 'holistic' approach

'I want to be able to choose lots of places to go and things to do.' Self advocate

James and his parents have short breaks service for up to 28 nights each year. James goes away for a weekend or a week-long break to one of the 3 bedroom 'respite' bungalows run by the Local Authority in a nearby town. James really enjoys these breaks, being away from home, meeting new and old friends. His parents need this regular planned breathing space, the chance to 'do their own thing' and recharge their batteries. However as older carers, James' parents are also thinking about the future and see the short breaks service as a key part of planning ahead. "If you ask us about James having his own place we'd say 'not yet', but this is part of working towards it. We know we won't always be around. To get James used to being away from his parents and the family home, it means we won't be starting from scratch."

RESIDENTIAL SHORT BREAKS

Residential short-breaks or respite is the most well known type of short break for people with a learning disability. These can be small and homely or large and institutional: *"the staff call it a unit and it is supposed to be our holiday."* Self advocate.

Many people with learning disabilities and their families feel that residential short breaks are important to them and they want them to be available locally. If a family has used a residential respite centre for many years, likes the staff, and relies enormously on these breaks, then this is hugely valued. However they do not suit everyone.

Residential short breaks need to be carefully managed so they offer as much flexibility as possible to people in terms of when they have a break, who they share the house with and who they have supporting them - these choices are very important and are some of the features that distinguish good from poor quality residential support.

For some types of break, and to meet particular needs and wants (e.g. people with complex needs) some accommodation may need to be purpose designed or commissioned. Existing accommodation can be remodelled to provide more flexible property and support meeting a broader range of needs. Commissioners and providers should ensure full accessibility to all areas of the accommodation, not just entrances, bedrooms and bathrooms and allow for specialist equipment.

HOTEL IN THE PARK, TOWER HAMLETS

“Staff are there to serve you.” Self advocate

Hotel in the Park is a hotel, where people with learning disabilities are guests rather than service users, taking a short break in their home city.

The Camden Society developed the hotel in response to a tender for respite services from Tower Hamlets Social Services. Camden Society took a different approach to bidding for the contract by asking people with learning disabilities and families what they wanted out of a residential respite service. The things that people said they wanted added up to an ordinary holiday experience so a hotel became the obvious solution.

There are seven en-suite rooms within the hotel and two of those rooms are completely adapted and include overhead tracking and hoists. All of the rooms have televisions and music centres. Guests can opt to eat their meals, prepared by a chef, in their own rooms or in the guest dining room.

The guests are referred through Tower Hamlets Social Services, and are allocated a number of nights per year. The hotel has four female only weekends so this opens up the hotel to women from the local Asian community who would not ordinarily use residential short breaks services.

It has not cost the Local Authority anymore to run this service than it does to run an ordinary residential short breaks service. This is possible simply because of an organisation that actively listens to what people want and uses imagination, takes a few risks and has the determination to make it succeed. Feedback from guests in its first 18 months has been very positive.

For more information: www.thecamdensociety.co.uk

Contact: John Crawford, Director of Services, 020 7485 8177

HOLLY COTTAGE, WEST SUSSEX

Holly Cottage is a small residential short breaks service provided by West Sussex County Council. It is a three-bedroom house on the same site as a larger short breaks service and provides a service for people with complex support needs.

The service supports a maximum of two people at a time. The staff spend a lot of preparation time co-ordinating the short breaks to ensure that not only are people matched with people they like, but that there is also consistency of support staff. The staff team come from a pool of staff that have provided specialist support for people with challenging support needs who live in their own homes or residential care. This ensures flexibility and expertise in providing the support to people.

The people who are referred to Holly Lodge for short breaks are usually people who cannot get short breaks elsewhere.

Contact: Mark Stables, 01903 839050 or email: mark.stables@westsussex.gov.uk

FAMILY BASED BREAKS

Shared Care, Person-to-Person and Adult Placement Schemes are where either another family or an individual offers short-breaks (and long term accommodation) to people with a learning disability in the carers own home. The schemes recruit, train and match carers with people with a learning disability in their own community. The carer usually supports one or two people at a time and may provide the break in their home overnight, or during the day, evening or weekend.

Sometimes the person providing the break goes to the person's own home, or supports them elsewhere in the community, offering a further level of flexibility and responsiveness. Adult Placement Schemes often have added value for people with learning disabilities and their family carers as they are able to build up strong and supportive relationships with the host family or carer, who may also be willing to help the family in time of crisis.

WEST SUSSEX ADULT PLACEMENT SCHEME

The West Sussex Adult Placement Scheme supports people with learning difficulties to stay with individuals, couples or families for long and short periods of time. Twenty carers specifically provide short breaks for approximately 60 people. The breaks take different forms: some people stay with a family or individual and just do ordinary things with the family for anything from a day to a few weeks. Some carers provide a holiday to people in their home and this can be as little as a B&B type arrangement with a bit of support, to a fully supported holiday. The scheme has carers that live by the sea, in rural areas and in picturesque villages so they make ideal places for a holiday.

The scheme also provides an outreach service to either support people in their own homes or to support them out and about in their community. They can also provide emergency respite.

The scheme is able to support people with more complex support needs and people needing accessible accommodation and people with challenging needs because they actively look for carers that can make this work. They have carers with ground floor accommodation and accessible homes, they also have carers with mental health and nursing backgrounds who are highly skilled at supporting people with more complex needs.

As one of the Department of Health Individual Budget pilot schemes, more and more people are using their individual budgets or direct payments to purchase short breaks through the scheme. Some people also fund the break themselves if they want more than the 28 days a year they are allocated.

Contact: Mark Stables, 01903 839050 or email mark.stables@westsussex.gov.uk

HOME BASED BREAKS

Home-based breaks are generally when a person receives one-to-one support within their own home to give the family carers a complete break from caring. Some home-based breaks also offer flexibility to the person to stay at home or to go out from home to places they enjoy.

CROSSROADS

Crossroads carers support scheme is provided in many parts of the UK. It is often described as a 'sitting' service. The local schemes vary but the main emphasis is on providing practical support to carers in the home. Usually a support worker will take over from the carer to give them time to themselves. It is a flexible service that can meet the needs of the family with the aim of giving the carer time to use as they wish - to see friends, keep appointments, study, read or even just to sleep.

For more information, go to www.crossroads.org.uk and use the 'scheme finder' to locate services in your area.

COMMUNITY, SOCIAL AND LEISURE BREAKS

Community, social and leisure breaks come in many different forms but the focus is always around an activity and often supports people coming together because of shared interests. People may be supported to go to disability focused or mainstream clubs or societies. They may attend activity groups for people with a learning disability that develop or build on an interest in the arts or sports.

Community based breaks are also being used specifically to help people form friendships and a larger social network that can be maintained outside of a service.

NATURAL BREAKS, MERSEYSIDE

Natural Breaks set up in Liverpool in 1991 (as a joint initiative between Social Services, the Health Authority and Mencap) to reach out to people who declined traditional respite for various reasons, or who were considered too demanding of service providers.

In the **Social & Leisure** service, they work with individuals who need one or more people to support them. Staff meet families and individuals where they live and support the person with a disability to get out regularly and to be included in different things, such as: going to college or classes, sports or exercise, employment or voluntary work, hobbies, days or evenings out, meeting up with groups.

The social & leisure breaks are regular and frequent, and tailored to the individual needs of the person and the family.

The **Out & About** service is offered to people living at home with parents or carers that have little opportunity to go out. They are supported to go out with a small group of friends with similar interests. Usually a support worker will work with 3 individuals enabling the small group to access leisure activities in which they are all interested.

Priority is given to older and lone parents who get little or no support from other sources.

The support staff at Natural Breaks also provide informal support for the family carers by making sure they are regularly in touch with families and signposting them to other sources of support.

More information: www.naturalbreaks.co.uk

Contact: Jan Swan, email jan.swan@naturalbreaks.net, Tel. 0151 207 9120

“Unless you’re there for the family, you don’t get to first base with the person. For the person to have a valuable short break and get benefit from it, you have to have a trusting relationship with the family. And if the person is doing something they enjoy, the carer gets a quality break.” Jan Swan, Natural Breaks.

THE ETHNIC MINORITY ACCESS AND PARTICIPATION PROJECT (EMAPP), SOUTHALL, MIDDLESEX

Part of the EMAPP National Mencap project, the Weekend Leisure Activity Service is a community based short breaks service for people from one Asian community in the London Borough of Ealing. The service runs every Thursday evening and alternate weekends from 10 - 4. It has a base in a local community centre that is situated in the centre of a large Asian community in Southall.

There is a range of activities that are planned over a six-month period by the people who use the service, mainly using local community facilities as well as activities based at the community centre such as arts & crafts, cooking, using computers, cooking and playing pool. Volunteers assist with trips out, and the service has two paid support workers who keep in regular contact with families and who have built up a great deal of trust with families that has not existed with professionals before.

The service supports 16 people and has a waiting list. It has female only groups and mixed sex groups. Some referrals have come through social services but most people have self-referred through word of mouth and by the project manager actively seeking out people and visiting them at home or contacting by telephone. Most people do not use any other short break service.

The service is funded by the Learning Disability Development Fund.

Contact: Tel: 020 8232 1590/1596 or email alka.trpathi@mencap.org.uk

SUPPORTED HOLIDAYS / RESIDENTIAL ACTIVITY BREAKS

*“ We want to help carers think beyond traditional respite. For some people, they could have a fortnight in Spain for the cost of a week in one of our residential homes.”
Commissioner*

There is a range of ways that people with a learning disability can be supported to have a holiday. There are several special holiday venues for people with disabilities, supported holidays where schemes provide support staff to go on ordinary holidays and activity-based or themed breaks. Some examples are given below. There is also growing availability of self-catering accommodation in holiday destinations in the UK and abroad that provide adapted and user friendly accommodation.

“I want to go on holidays with people, not just to care homes.” Self advocate

CALDER BREAKS, WALES

Calder Breaks is a holiday breaks service individually tailored to small, friendship groups of young people. The service was set up originally for 4 young people going through transition who wanted to spend time together on holiday. Calder Breaks owns two caravans, fully adapted for wheelchair users, based in different holiday parks. They also support young people to take holidays in other holiday resorts.

Some of the holiday breaks are purchased by social services; others are purchased directly by families and young people using direct payments, ILF, benefits and family contributions. The service meets the criteria for ILF as an important part of the break is for the young people to get fully involved in running their holiday home and getting a chance to learn and practice new skills. It is also an opportunity for young people and their families who are beginning to plan their future away from the family home to think about whether they would like to share a home and about potential housemates.

Further information: Will Cubbon, 0151 280 6155

LING TRUST, CARROG MILL, NORTH WALES: TAILOR MADE HOLIDAYS

The Ling Trust owns three holiday cottages in North Wales to enable people with learning disabilities and families to enjoy tailor made holidays in a beautiful rural environment. The Ling Trust used charitable funds to renovate and adapt the cottages, making one completely accessible for wheelchair use.

Carrog Mill is also used as the base for the team who are developing individualised budgets in Wales.

The flexible holiday options allow families and people with learning disabilities to self-cater, to bring their own supporters, or to have support provided for the holiday period. Part of the scheme is focussed on training and supports people to learn independent living skills or to learn employment skills locally.

Ling has recruited and trained local people to support people with learning disabilities to have a break in the way that they want. The staff are not employed but are available on a ‘bank’ to provide support in their specialist area, such as teaching independent

living skills, or nursing care for those who need it. They also provide Welsh speaking staff.

Further information: Jayne Knight, jayneknight@thepantiles.co.uk, Tel 01206 769246

CARERS BREAKS, LAMBETH MENCAP

This project enables family carers to have an enjoyable rest at home by providing their family member with a creative programme of activities and holidays. The service is provided for 85 families and about a third of those families support sons or daughters with very high support and healthcare needs. It organises ten holidays per year, which enables 60 people with learning disabilities to have a holiday.

The project succeeds because it combines high quality holidays and activities with detailed attention to individual needs. Carers Breaks supports people with a wide variety of needs including people who have complex health problems, people who have mobility needs and/or physical disabilities, people who are tube-fed or insulin-dependent, or those who might have individual transport needs.

Project staff have worked closely with families of people with very high support needs to enable them to have equal access to the project, including people who have no access to other forms of respite care. They have worked successfully with many families who have moved from having no respite (because of previous bad experience or lack of available services that could cater for their family member's complex needs) to being prepared to let their son/daughter to go on holiday.

Carers Breaks also organizes outings and activities such as going to museums and galleries and theatre workshops, similarly spending a lot of time researching places and venues to ensure that the outings have meaning and enjoyment for all the people that go. Much emphasis is placed on working with staff in mainstream arts and leisure facilities to support them to make their services accessible and enjoyable to people with learning disabilities.

The project also provides a wide and creative range of evening and weekend activities that provide family carers with a short break of a few hours. The activities on offer to service users include sailing, theatre and dance workshops, reflexology, storytelling and many more.

Further information: Becky Loney on 020 8655 7736, email: becky@lambethmencap.org.uk

You can get a booklet of supported and inclusive holiday providers including useful tips, contacts, information about benefits and funding from HFT's Family Support Service. Download the publication from www.hft.org.uk/data/asset/file37.pdf or telephone 0117 930 2600.

*“We went to a place where we got help to have a holiday -we took a train and got help from the people who work on the trains. You feel really good doing it on your own.”
Self advocate and his wife*

SELF DIRECTED SHORT BREAKS

Self directed short breaks are where a person and family organise a way of having breaks around their own needs and they do not necessarily use a traditionally organised short break service. The main reason that people want to plan and organise their own short break is that there are no short break services in the area that meet their needs. It can also be that the person wants or needs something that is so individual to them that they are unlikely to get what they want and need from a short break service.

People are making their own short breaks happen in the following ways:

- Using Direct Payments
- Getting an Individual Budget
- Using the Independent Living Fund
- Paying for help themselves
- Using volunteers to help

USING DIRECT PAYMENTS

Olivia is 27 years old and lives with her parents, Gaynor and Brian. Her experience of residential short breaks was not good, and eventually she refused to go. With no local alternatives the family had no short breaks until Gaynor heard about direct payments at a conference. She asked Olivia's care manager if they could be used for short breaks and was told no, they were only for people with physical disabilities. Gaynor refused to accept this and went directly to the organisation that ran the direct payments scheme. This led eventually to Olivia getting a direct payment for 15 hours support a week.

Olivia and her family get breaks by saving up the 15 hours and using them for the occasional weekend away, a week long holiday every two years, and more regular support for Olivia to go out to clubs and other activities during the week. Olivia employs a Personal Assistant (PA) to go on holiday with her. Her PA's wages are paid for by direct payments and her family pay the PA's expenses, hotel travel and entertainment costs

Olivia and her family are happy with what they have achieved by using Direct Payments, but Gaynor admits that it is not easy. She has had to plan activities and co-ordinate the rotas for the P.A.s to stay at her home to enable her and Brian to have weekend and holiday break. If there was a local service that could provide flexible and good quality support and get the same outcomes for Olivia and her family, it would be a lot easier.

"I have to fight for funding for every break we have. Each night has to be funded by going cap in hand and there is never any guarantee that you will get the direct payment needed to fund the PA: bring on In Control!" A mum

INDIVIDUAL BUDGETS FOR SHORT BREAKS

Neil is 26 years old and lives at home with his family in the Midlands. Neil has profound and multiple learning disabilities and health problems that mean he needs to have a constant oxygen supply.

Neil and his family have been allocated an Individual Budget under the In Control programme. Neil and his Mum, Calpretta have been using a support broker to help them plan the best way to get a break. Breaks are really difficult for Neil because he needs specially adapted accommodation and equipment.

The solution that the family have come up with is to buy a holiday home by the sea in Torquay, Devon. The home has been adapted to meet Neil's needs. Neil and his family employ two carers who take Neil to the holiday home for one week in every six weeks. Neil's family can also stay at their holiday home which means that they can spend quality time together as a family without the pressure of having to be in a caring role as well.

Neil also uses some of his budget to pay carers to take him out twice a week when he is at home. Neil has a mixture of Independent Living Fund and money from social services that makes up his budget allocation.

SHORT BREAKS WITH THE SUPPORT OF A VOLUNTEER

Paul is 40 years old and lives with his parents. He does not like to use ordinary short break services. Paul just likes doing ordinary things in his community and does not want to use learning disability specific services.

Paul and his dad enjoy stock car racing and they have been going together since Paul was a teenager. For the last few years, Paul's dad has been ill and has not been able to take Paul out.

Paul's parents looked for someone else to go with Paul to the stock car races - they were happy to pay another person's entry and travel expenses but it was hard to find someone who was prepared to go without being paid. They went to the local voluntary services council who put an ad in their newsletter for a volunteer. They soon found Jim who was a regular at the stock car races as well as being a local volunteer. Jim was thrilled to be going to the stock car races with Paul and to be paid travel expenses and entry for something he loved doing anyway.

For the last five years, Paul and his family have had a break for the day twice a month when he and Jim go to the stock car races - they sometimes go with Jim's son or his friends and Paul has had a new social network opened up to him. Paul's parents are happy because they know that he is having a great time as well as being well looked after.

EMERGENCY BACK UP BREAKS

Every Council area should have an emergency break service available. Some Local Authority areas include arrangements for emergency back up for family carers when thinking about short breaks. This forms an essential part of holistic support for family carers, as it is often a source of great anxiety. Where schemes are developed to meet the needs of carers in general, it is important to recognise that emergency carers need to be trained and able to work with people who have a learning disability.

Just as it is important to offer choice of short breaks, families need to be supported to access emergency back up arrangements that suit them and the needs of the person they support. The emergency can happen at home and so the break may need to involve the person with a learning disability coming out of the family home for a period. The New Deal for Carers will cover home based respite in emergencies. However some emergencies may mean the person with a learning disability needs to stay away from the family home for a while. Local Authorities will need to ensure that they top up the emergency respite funding from other sources to ensure all types of emergency are provided for.

One family member described her ideal emergency back-up arrangement:

“I would like my direct payment to recognise this need [for emergency back up] and include an amount that I could give as a retainer to a support provider whose staff I would trust in an emergency. The retainer fee would cover some staff getting to know my daughter so that in an emergency she would not be faced with a total stranger to care for her.”

EXAMPLES OF EMERGENCY BREAKS

Carers Emergency Respite Team (Cert): Sefton Carers Centre

Sefton Borough Council commissions Sefton Carers Centre to provide the Carers Emergency Respite Team (CERT). This service offers an instant response when a carer faces an emergency, which would prevent them from continuing to care, such as sudden injury, illness or unplanned hospital admission. Within an hour, a briefed member of the team will appear and take over the caring role. The team can provide a series of ‘pop in’ calls or a total move in, up to a maximum of 48 hours. If further support is required the team makes a referral to the most appropriate agency and liaises with family and friends if necessary. An important feature of the service is the advance care planning carried out when a carer registers with the service, so that everyone is clear about individual needs and supports that would be needed in an emergency.

Contact: Dilwyn James, Tel 0151 288 6060, email: help@carers.sefton.gov.uk

West Sussex County Council has a strategy giving options for people in an emergency: a family in its Adult Family Placement scheme is paid a small retainer to accept people in an emergency; the in-house floating support service supports people to stay in their family home in an emergency, which suits people with adapted accommodation or people with autism who find it difficult to go into new environments; an ‘older carers worker’ helps carers to make plans for emergency situations.

Contact: Mark Stables, Tel: 01903 839050 or email mark.stables@westsussex.gov.uk

Supporting older families: making a real difference published by The Foundation for People with Learning Disabilities is an excellent resource for Partnership Boards, with

lots of practical suggestions for helping carers to plan for emergencies including the 'Message in a bottle' scheme. www.learningdisabilities.org.uk

THE ONE STOP SHOP

A co-ordinated approach to short breaks, which still allows for choice and control is not easy to achieve. Commissioners, providers, families and people with learning disabilities want to achieve better awareness and co-ordination of short breaks options, as well as offering more choice. One approach to this is the 'one-stop shop model' providing information and support with choosing and accessing the most suitable short breaks.

Even where people had a direct payment, they said they would welcome help with the process of thinking about and arranging their short breaks. Some new approaches to co-ordination and brokerage are being established in the UK and beyond.

This approach can also include the development and *enhancement of local community websites* so that they provide information and links to all respite services available in the area. A Scottish Highlands local community website www.newtonmore.com/disability gives a good example of this.

THE TORONTO MODEL: RESPITESERVICES.COM

Funded by the Ontario Ministry of Community and Social Service, Toronto has a co-ordination service for its network of agencies & organisations providing respite services to individuals with all kinds of disabilities and their families. Once registered and knowing their funding allocation, families can contact agencies directly for assistance or ask for help in connecting to a respite option from an Access Facilitator. The *Access Facilitators* help identify the family's respite needs and will provide short term co-ordination to overcome barriers to receiving respite services. They will also assist with application forms (to agencies) and interviewing potential CHAP workers.

The *CHAP (Community Helpers for Active Participation)* programme recruits a large base of workers interested in supporting people with learning disabilities and autism to provide meaningful respite options through community based options. Families are able to make their own arrangements to purchase supports by connecting with workers (all checked and approved) and agencies are able to access workers to enable individuals to participate in community based short break options, support in the home, and support for holidays.

SHORT BREAKS AND OTHER SUPPORTS

Family carers want a choice of short breaks and they want to be able to pick and mix from different types of breaks. Many people with learning disabilities want this too. Some families also want options that they experience as short breaks, although they may not be defined as such by the Local Authority. These include:

- Shared breaks
- Assistive technology support
- Other support services, especially during the day

It is important that these needs and supports are considered creatively alongside short breaks, but not as a substitute for proper assessment and adequate provision to meet the family carer's need for a short break.

SHARED BREAKS

These are services or projects that support a family to have a break together. The breaks may be for day or evening trips out or to go on holiday. Extra support is provided so that the family carer(s) is not solely responsible for providing care and support.

"It's the opportunity simply to be with my son, to have time with him as his Mum, not his carer."

ASSISTIVE TECHNOLOGY

Assistive technology is a term used for any gadget or device that helps a person to be more independent. Assistive technology can also be used to support carers to care for a person with a learning disability.

While assistive technology does not necessarily replace the support of a family carer, it can help make caring easier and be a vital complement to a short breaks service. An example is that various 'Telecare' sensors in the home may help the carer and the person they care for feel more comfortable about popping down to the shop and leaving their son or daughter with epilepsy at home, safe in the knowledge that if they have a seizure, an ambulance will be called and the carer will be alerted straight away.

For more information: Foundation for Assistive Technology, www.fastuk.org.

TIPS FOR PARTNERSHIP BOARDS

Essential ingredients for all short breaks

- Trained, caring, respectful and friendly staff able to establish good relationships with families and people with learning difficulties and to use their strengths and talents.
- A continuous link with at least one carer so that the person with a learning disability and their family can get to know them well.
- Where groups are involved, these should be small, giving people the chance to stay or meet at the same time as friends of the same age and sex and get help to make other friends.
- Arrangements are in place to enable families to plan ahead and have regular patterns if that is needed.
- The service design should build in flexibility and allow for changes.
- It is person centred - services are run in a way which suits individuals, even within a group. Service providers make sure that people who do not like each other are not in the same groups.
- Positive risk assessments involving staff, users, carers and professionals are used, especially to help people with the highest support needs to have ordinary breaks.
- There is regular consultation with users and carers about the project or service, which listens to them and stays flexible.

For good residential short breaks

- A homely or 'hotel' environment, not an institution, e.g. domestic in style and scale.
- Located close to community facilities or with good transport links or transport provided.
- Fully accessible where possible for people with physical disabilities and complex healthcare needs.
- Accommodation can serve as a base for a range of flexible person-centred supports, activities and outings.
- Attention is paid to getting the basic 'hotel' services right (laundry, meals) or supports to assist people with laundry and cooking where this is what people want.

For good family-based breaks

- People offered the break feel like part of the family.
- Carers are recruited from local communities so that people can stay in their own community, able to continue routines that are important to and for the person - if this is what they want.
- The breaks should also offer the potential for new experiences and friendships.
- Ideally, the service builds in the capacity for an emergency back-up response.
- A wide net is cast when recruiting - pro-actively looking for carers from minority groups and advertising in the right places to recruit people who can support people with complex needs.

For good community, social, holiday and leisure breaks

- There is a thorough search for suitable locations for holidays, outings and activities (and staff will be prepared to visit places before they are booked).
- The service is dynamic, with new activities and locations regularly introduced.
- It uses the resources and people within the local community.
- People (family carers and people with learning disabilities) are supported to make and sustain friendships, personal and community connections in ways which reduce reliance on the service for social contact.

5 ESSENTIAL INGREDIENTS

Getting better short breaks for people will take leadership, commitment and action. It needs thoughtful commissioning strategies and creative use of funding and other resources.

THE BASICS

Knowing the needs in your area and having a range of options which meet these is essential. These need to include options for those who are often left out when choice is limited. Family carers and people with disabilities should be able to make the decisions on which option, or options, to choose. Learning Disability Partnership Boards and others can take steps to make this happen.

- Explain clearly what your area considers a short break to be.
- Do a full audit of provision in your area, with health partners.

- Develop a range of options targeted to meet the particular identified needs in your area.
- Ensure that specifications reflect our key tips above.

LEADERSHIP

“It takes leadership - someone with the authority and responsibility for developing this - otherwise it’s death by task force.” A Commissioner

Learning Disability Partnership Boards can make short breaks a development priority, giving it a high profile and defining the results required.

Families and people with learning disabilities can and should be involved in improving and developing short breaks services to meet their diverse needs. Consultations are certainly a means of involving and including the people who need short breaks. However the most effective consultations have been those that included families and people with disabilities from the very beginning.

However, it is even more vital that Partnership Boards and Local Authorities act on their findings. Research on its own achieves nothing.

ACCESSIBLE INFORMATION ON LOCAL AND WIDER OPTIONS

“A booklet or website of recommended places and how much help you get would be good, and an information service like a holiday booking website so that short break services can be accessed in other areas.” A Mum

Families and people with learning disabilities, care managers and social workers all need up to date, timely and accessible information about short breaks options, carers assessments, how to access services and alternative options.

Tell people what the options are and help them to understand these. This means that information needs to be provided in different ways and alternative formats, including:

- Written information booklets
- Easy read information
- Posters
- Telephone hotline
- DVDs
- Verbal advice
- Web-based information and interaction.

Valuing People Support Team’s leaflet for families **“What’s in it for you?”** gives families clear and accessible information about Carers Assessments and a checklist to prepare for the assessment. Valuing People Support Team is also producing a leaflet of people with learning disabilities to complement this.

TRANSPARENT ASSESSMENT AND ELIGIBILITY PROCESSES

Carers have a statutory entitlement to a carer's assessment, but not to receive a service. Even if assessed as eligible, they may find there is no suitable or available service that suits their needs. This can be a frustrating experience for families.

Aim to be clear and quick about telling people what level of service they can expect. Ways of improving the transparency, simplicity, quality and equality of assessment, resource allocation and outcomes include:

- Simple self-assessment and resource allocation: the In Control approach for carers (www.in-control-org.uk).
- Parallel assessment of family carers and the person being supported.
- Points systems based on assessment criteria determining eligibility and level of support to be offered.
- Telling people their annual allocation so they can plan ahead.
- Support for an independent brokerage service able to help the family and individual plan how to spend their budget.
- Support for voluntary organisations able to give short break experiences on a self-referral basis.
- Tell people what they can do if they do not agree with the level or kind of service they are offered e.g. how to appeal or complain.

Mencap's Minimum Standards Guarantee is a simple way for councils to give equal support to families with equal levels of need in an open and fair way. It is based on a person who lives with their family and is getting the Disability Living Allowance (DLA) care benefit. For more information and a copy of Mencap's Breaking Point research, go to www.mencap.org.uk/html/campaigns/breakingpoint

LOCAL JOINT COMMISSIONING STRATEGIES

A clear commissioning strategy for responsive and accessible short breaks, which focuses on outcomes rather than only on process or types of provision, will give a necessary framework for developing good quality, value for money services. It can make sense to carry out a joint audit and review with health partners and joint commissioning of new services. Similarly neighbouring Local Authorities can consider joint commissioning or purchasing of a short breaks service where this will maximise its use and benefit.

- When commissioning short breaks, families and people with disabilities are clear about what they value and these ingredients can be included as service requirements (box on page 23).
- People receiving breaks from a building-based health unit, managed and staffed by an NHS trust usually value the commitment of trained and consistent staff. At the same time they recognise that health provision often offers very limited opportunities for social support, and that there seem to be few alternatives: "*It is the best of the options around*". The examples in this document suggest alternatives. Specialist health staff may be able to support other services by providing a peripatetic service
- It will help to be clear about how you are going to support people with Aspergers and others that may not be eligible for services, for example a 'flexible funding pot' which could be managed by a voluntary sector provider.

- Look at ways of linking strategies for, and learning from, children’s short breaks services, and ensure consistency in commissioning arrangements so that there is not a sudden change in pattern or availability of short breaks for young people in transition - especially those with complex needs.
- Where changes are planned, include carers and people with learning disabilities in the process. Listen to their fears that an essential service may be withdrawn without adequate plans for alternatives having been developed and set up, and address this.

South Sefton PCT works in partnership with the local council so that where a person has a recognised health need, the PCT targets additional resources as required. In addition, the PCT supports and trains staff in residential respite to develop necessary skills and knowledge; and makes clinical resources available to meet individual need; it can also provide this input in the family home to enable home-based short breaks.

“If someone with complex health needs goes for residential respite and does not access the trained staff needed, then their health can deteriorate. If we can put in additional resources, it prevents health deterioration without requiring the person to stay in ‘health respite’.” Geraldine O’Carroll, Sefton PCT

Contact: geraldine.ocarroll@southsefton-pct.nhs.uk

*“If we support people when they’re strong, they’ll stay strong longer. Yet we apply FAC criteria that means people don’t get the support until their need is urgent. There’s an unresolved tension there - we need a clear commissioning strategy that addresses this.”
Local Authority Commissioner*

Over the next year, the Council for Disabled Children will be developing commissioning guidance on short breaks for disabled children on behalf of the Department of Health.

FOCUS ON OUTCOMES

- Monitor performance of providers against outcomes agreed with the family and the person supported.
- Avoid attending only to the challenge of how people get the break and focus equally on what they want to get out of a break. People may choose to buy equipment that makes life easier and gives them more quality time with the family. An extension to a domiciliary care package can provide support to help a carer get away, or even just get a night’s sleep.
- Different approaches to funding, including individual budgets make it possible for everyone who is eligible to get a short break that suits them.
- Investing in preventative short breaks can lead to long-term savings in social and health care for the carer as well as the person with a learning disability.

CONNECTING WITH OTHER SOCIAL AND HEALTH SERVICES, MAINSTREAM AND COMMUNITY SERVICES

Short breaks services often complement other supports, services and amenities which the family or person with a learning disability uses or could use.

- Look at how your day services and community care services might link with or provide short breaks as part of an integrated support or care package.
- Invest in building the capacity of community services such as library services, swimming pools, gyms and clubs to open wider opportunities and supports for short social and leisure breaks.
- Use the information and expertise available within local voluntary services, Carers Centres and Centres for Independent Living.
- Set up ways to cross-fertilise good ideas from services for other groups e.g. older people and children's services.

MAXIMISING FUNDING

Some funding sources cannot be used to pay for accommodation, so where accommodation and support are provided as a package, as in residential short breaks, this limits the possible funding sources for short breaks. Direct Payments, Independent Living Fund, Carers Grant and New Deal for Carers Grants are just a few of the funding possibilities which can widen the options available and increase choice and control for families and individuals.

- Don't tie up all of your resources in block purchases or residential short breaks. This restricts choice and flexibility. Maintain a funding pot to enable flexible short breaks, and also make sure people can still access good quality residential breaks if needed.
- Encourage and work with providers who offer creative ideas and contributions. There are examples here illustrating how providers are securing and investing capital funding to provide quality accommodation as a base for flexible short breaks and revenue funding to develop innovative approaches.

The options described in the guide are paid for with money from one or more of these sources:

- Carers Grant
- Community Care funding
- Health funding
- Independent Living Fund
- Family contributions
- Individual's money (incl. benefits)
- Corporate (i.e. Business) Sponsorship
- Fundraising
- Voluntary contribution - time, resources
- Preventative Technology Grant
- New Deal for Carers Grant
- Learning Disability Development Fund
- Capital grants or loans for accommodation

The money has been distributed in different ways:

- Direct Payments
- Individual budget
- Block contracts for commissioned pre-purchased services
- Spot purchase contracts for individual services

OFFERING CHOICE

“ We want to help carers think beyond traditional respite. For some people, they could have a fortnight in Spain for the cost of a week in one of our residential homes.”
Commissioner

Put systems in place that let families and people with learning difficulties lead the decision-making about which short break options will meet their needs. Examples include points schemes, voucher schemes and direct payments. These need to be supported by providing full information on the range of options and clear information about what level of short break people can expect.

Some areas ask carers to make decisions at the start of a year about how they want to spend their points or vouchers, to assist the Local Authorities with contracting arrangements and pre-purchase of services. Some offer the option of mixing the routes e.g. taking some of their allocation as points, and some as a direct payment, which further improves the flexibility and control for families and people with learning disabilities.

Points and voucher schemes only improve choice if there are enough options and providers able to offer tailored and meaningful short breaks for people who have more complex or healthcare needs.

POINTS SCHEMES

Instead of offering a fixed number of nights break in residential respite, generally over a year, carers are allocated a number of points, based on assessment of their needs. The points have a monetary value and carers can ‘spend’ or invest their points on one or more short break options from a menu offered by the Local Authority. Barnsley County Council has introduced such a system, as part of its wider review of short breaks services, and has had positive feedback (see below).

DIRECT PAYMENTS

Carers can choose to take some or all of a points value as a direct payment. Other systems that allocate a number of ‘nights’ respite, can be translated into a monetary value and offered as a direct payment.

VOUCHER SCHEMES

Some Local Authorities have developed, or are developing carers voucher schemes for home-based support and/or residential supports. Some areas restrict use of vouchers to Local Authority provided services, while others enable access to services offered by approved independent sector providers. Liverpool, Sefton and Bury County Councils are a few of the authorities that offer a voucher scheme. These give carers flexibility in arranging short breaks for themselves and the person they care for. Carers can ‘spend’ the vouchers with any approved agency. The ‘time value’ of the vouchers varies between schemes but is commonly for one hour. After assessment and access to the vouchers, carers do not need further contact with Social Services. Carers and individuals feel this system offers them more choice and control in arranging breaks.

BARNSELEY: WHOLE SYSTEM REVIEW

Barnsley is one of several authorities improving short breaks for carers and people with learning disabilities. The closure of a residential respite unit and a consultation process with carers which highlighted that the existing system was unfair and lacked choice provided the urgency needed to introduce change.

Work has focused on:

- Developing a fair and transparent approach to assessing need and deciding on eligibility for services. This resulted in the development of a scoring system, with the number of points scored determining a number of 'nights' respite, capped at 8 weeks in a year. A 'night' can be turned into a number hours, which can be turned into an amount of money.
- Identifying new sources of funding, including ILF, and ways for people to have more direct control through Direct Payments.
- Widening the options: commissioning of 4 small accommodation based services for 2 people each; an in-house Adult Placement Scheme; outreach work; and, following a tender process, commissioning Mencap to develop a holiday service, offering 10 supported holidays a year at fixed times.
- Designing a more flexible approach for carers to use their 'points', including taking all of this as a Direct Payment, or taking some as a Direct Payment and using some for residential respite and a supported holiday.

Early feedback is positive. Under the new assessment system, 80% of people are getting more time for short breaks and fewer than 10% of people are getting less.

Further information: Joanne Price, email joanneprice@barnsley.gov.uk, tel. 01226 775819

HELP WITH PLANNING AND ARRANGING SHORT BREAKS

Even where people had a direct payment, or vouchers or points, many welcome or need help with the process of thinking about and arranging their short breaks. The one-stop shop model, page 22, is one way of supporting people to have choice and control. Others to think about are:

- **On-line booking systems** for locality based services
- **Travel agency or bureau approach** for directly funded short break options
- **Brokerage services**

SMART BREAKS BROKERAGE SERVICE

Smart Breaks is a brokerage service for short breaks for disabled people and their families run by The Thistle Foundation in Scotland. Using person centred planning, an independent broker helps and supports people to plan a more meaningful break, designed to meet the individual's own interests and needs.

Some people are referred to the service, or approach it, having been given a direct payment from the Local Authority to support their break and seek help to plan this. Others hear about the service from leaflets and posters in libraries, community centres and surgeries and can make direct contact. The brokerage service can assist people to design alternative breaks and options, whether or not they have identified funding to pay for this. Part of the service includes providing information on possible sources of funding, and assisting with forms if necessary. The Thistle Foundation does not itself provide short breaks.

At present the service is funded by a corporate sponsor, and employs a part-time broker.

Contact: Sylvia Dow, email sdow@thistle.org.uk, Tel 0131 656 9947

Kate and her family live in St. Andrews and wanted to discuss the possibility of Kate having a short break away from her family. She had never done this before. Over some months, Sylvia, their broker, spent time with Kate and the family exploring her likes and dislikes, routines and what was important to her. Kate decided she would like to visit her aunt in Liverpool. The service helped her plan to fly to Liverpool. They helped the family to find a local recommended support worker, who met Kate from the plane and supported her to make the most of her trip.

Kate's mum, Judith, went away for her own break. She missed Kate at first and called to see how she was getting on. When she knew Kate was safe and enjoying herself, she was able to relax and unwind herself.

6. SHARING INFORMATION AND BEST PRACTICE

Valuing People wants to encourage families, Commissioners and providers to share their learning about short breaks. Its website offers a forum for sharing resources and good practice.

Several Local Authorities have undertaken their own research into the literature in this subject, the range of options and the experiences and views of people in their area. You can find these and other examples of successful short breaks on www.valuingpeople.org.uk

Short breaks will also be discussed at family carer regional meetings. Partnership Boards should ask their family carer representatives to report back, as well as sharing progress and pitfalls.