

## **Delivery of user-friendly respite provision for people with learning disabilities**

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Respite care for carers is something which has been recognised as important for the last two decades, although provision has often been un-satisfactory for both carer and service user. The delivery of respite provision which is user-friendly, providing a benefit to the service user as well as the carer, is something more recently recognised, and guidance is slowly being produced.

Searching for information about respite care for people with learning disabilities, it becomes apparent that there is not a great amount of academic research into the subject, but more evidence of practice from local councils. That said, the late 1990s saw some particularly relevant pieces of research studying types and experiences of respite care. There is rather more research looking at the carers' experiences of respite, with research highlighting their problems with having to fit into existing inflexible systems, the lack of emergency care, and how poor respite provision often does little to alleviate stress producing rather feelings of guilt (Stalker 1996). Again, though, there is very little about the experiences and views of people with learning disabilities in relation to respite care.

Following on from the 2001 *Valuing People* White Paper, there was a re-assessment of respite care provision, which has then produced a range of evidence of different models at local authority level, and guidance from the Valuing People Support Team. That said, it has not been swift to happen – guidance was only issued in 2007.

This paper will outline the concept and history of respite care before looking at what a user-friendly approach is, and how to combine the two. It will then summarise existing guidance on how local authorities can put such an approach into practice before giving examples of current practice from Councils across England, Scotland and Wales.

### **What is respite care?**

Traditionally, respite care has been provided to give carers a break from caring. The emphasis was on helping the carer continue to care, "relieving care burden" (Cotterill et al 1997). This is a long-held view of respite services, which is held up through policy documents throughout the 1980s and 1990s, and in the type of services provided. These services tended to focus on taking the person with learning disabilities away from their home setting, supposedly giving the carer the space to relax and focus on themselves.

Respite has therefore often consisted of people with learning disabilities having short stays in long-term residential care homes. A study carried out by the Joseph Rowntree Foundation in 1996 found that the majority of social services departments reported the availability of residential respite care for people with learning disabilities and that this was the most commonly used form of respite

care (JRF 1996). There is however, extensive evidence that demonstrates that this type of **“mixing” of service provision is detrimental to the care of both those in the existing long-term facilities as well as those receiving short-term care** (Stalker 1997).

Since the late 1990s there have been increasing calls to move away from the idea of carer burden, to the idea of respite providing space for both parties – the carer and the cared for. For many, the concept of respite as alleviating a burden is insulting to the person being cared for, as well as to carers many of whom fail to feel the stress-relief they are supposed to when “relieved” of their burden. Carers feel concern about the welfare of their loved-one during their time in respite, and have been as unhappy with the facilities provided by many respite care scenarios as have those experiencing it (Stalker 1996). As one carer said: “I want good respite, not any respite.” (Harrow 2003)

Cotterill et al, in their 1997 report into respite services, identify the different aims and benefits of respite reported on in existing research. From that emerges a re-framing of respite “around the needs and wishes of service users”. At the time (1997) this was only being recognised by the minority of service providers, but it then became an approach which would grow in importance throughout the following decade. There is the recognition that

“if the service is to be acceptable, the experience of respite should be positive for the person actually using the service as well as for the carer. Respite can provide positive opportunities for service users in terms of increased independence, a widened range of activities, improved quality of life and social integration in the community.” (Cotterill et al 1997: 777)

With this change in definition of the term “respite” comes a change in the terminology. For many, **a move towards the concept of “short breaks” and away from “respite” helps in removing some of the negative connotations.** A break is something that both people experience, and has positive connotations of new experiences and an enjoyable holiday (Stalker 1997). More recent definitions of short breaks are as something that

“provides an opportunity for users to make friends, interact with others and offers steps to independence.” (Gloucestershire Council 2007)

Or as something that “should provide an opportunity to try out different things, give people a chance to be themselves and be a real holiday” (Scottish Government 2006). Above all, they should be something that benefits everyone, both carer and the person who needs support and care.

However as is pointed out by Stalker, changing the name doesn’t necessarily change the experience. She goes on to say that only when “all short-term care services prioritise the objective of offering people enjoyable breaks and stimulating opportunities” will the “breaks” become less negative than “respite” ever was. (Stalker 1996) So in order to provide these positive experiences, the involvement of service users and carers in deciding what they need and want is vital. In other words, the services need to become user-friendly, with a person-centred approach.

## User-friendly or person-centred?

This study calls for an investigation into user-friendly approaches to respite care, but it is worth widening that into investigating possibilities of a person-centred approach. User-friendly services are those that are made easily accessible to the key audience, in this case, people with learning disabilities. They would therefore involve the provision of easily read documentation about respite care, facilities which meet the needs of those with a wide-range of physical and mental difficulties, and services which are easily used and accessed by the target audience. If we move that further to a discussion of a person-centred approach, we are looking at how to ensure that the services provided meet the needs and wishes of the service user and carer.

A report published on "Person and carer centred respite care for people with dementia" (2009), provides a useful summary of the key components of a person-centred approach. Particularly relevant to respite care is the concept of a service which:

- Involves service users
- Supports family relationships
- Provides a social environment that supports psychological needs
- Enables choice
- Listens
- Respects individuality and values
- Respects privacy and dignity
- Generates choice and control
- Emphasises the importance of relationships

In terms of defining a user-friendly approach to respite care, we are therefore looking at approaches which emphasise the involvement of the service user in decisions surrounding the care or break to be provided, producing short term care which focuses on the importance of the individual experience.

## What people want

Such a person-centred approach to respite/short breaks relates closely to the government's *Valuing People* White paper (2001) with its focus on choice and empowerment. A 2007 document by the Valuing People Support Team, provides a guide to short breaks for people with learning disabilities which stresses the importance of a person-centred approach to short breaks. In it, they use information from a range of different sources including service user and carer groups, questionnaire studies and interviews to identify *the factors which people feel make for a successful short break*. These factors include:

- Flexibility and responsiveness
  - Timely and accessible information
  - A service which is easy to access
  - Regular, frequent breaks
  - Many options offered which meet local need
  - Well matched staff, individuals and families, so that people can develop supportive relationships
  - Involvement of families and people with disabilities in service developments
  - Person centred planning used to identify what is best for the person.
- (Fitzpatrick & Wood 2007)

It is worth also looking at other examples of research which has demonstrated *what service users and carers want from short-breaks*. The Joseph Rowntree Foundation sets out some key components of respite services as defined through research done in Liverpool. According to this study, people felt that respite services should:

- Enable people to have control
- Offer good experiences and personal advantages
- Sustain feelings of personal worth and esteem
- Promote individual support as a result of individual planning
- Sustain people's significant relationships
- Be local
- Be responsive to the ideas and concerns of service users

(JRF 1996)

Whilst the Valuing People list appears to focus more on the practicalities of short breaks (e.g. accessible information, frequent availability of breaks etc) these factors emphasise the person-centred approach more than the practicalities, focusing as they do on enabling control, being responsive to ideas of service users, and promoting individual planning.

An *example from Essex County Council* provides key indicators of good quality respite care which appears to combine the other two approaches:

- Flexibility – providing choice and meeting changing needs but also being predictable and reliable.
- Being needs-led – meeting the needs of both service users and carers.
- Being part of a continuing programme of care
- Producing benefits for both users and carers
- Making information about services, eligibility criteria and costs readily available
- Design, planning and delivery of the service being treated as a partnership between the service provider, the person requiring care and the carer.
- Being affordable and accessible
- Taking into account cultural, ethnic and social class factors.

(Essex County Council 2006)

These lists provide us with some background as to what makes for well-received user-friendly short breaks, but what do these new types of breaks look like in practice? In the current shift away from traditional residential respite care to short breaks, a range of different options have emerged:

- Community based care – where the individual is supported in their own home whilst the carer goes away.
- Adult placement schemes – where the individual spends some time with a different family
- Befriending – where someone helps the individuals to enjoy social and leisure activities
- Holiday accommodation – for either the individual or the family as a whole
- Emergency breaks
- Day services – day care centres which provide a range of leisure activities
- Domiciliary services – help around the home for the family as a whole
- Residential services – in a range of different types of units, from "hotel" type accommodation, to units within long-term care homes.

New, innovative ideas are emerging all the time, especially in the light of the availability of direct payments, which many service users have used to decide on their own type of break. What is important is that there is a good range of options available, which meet the needs of the range of service users who will be using them.

## **Designing a user-friendly approach to short break provision**

The Valuing People Support Team provides advice on how local authorities can provide the most appropriate short breaks. They propose a menu approach, where local authorities identify the most suitable and feasible range of breaks to offer; with support given to ensure the service user and carer feel that they are making the right decision. In order to decide upon the types of services to offer, the Support Team suggest that the Learning Disability Partnership Boards ask the following questions:

- “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?
- Have you looked into additional sources of funding that can help in extending short break options?” (Fitzpatrick and Wood 2007)

If these questions are answered positively, if service users have been listened to, if funding sources have been established, and if available services have been audited, then the information is there to set out available options for user-friendly short breaks.

Moving from the information gathering stage to the practicalities of delivering short breaks, the Valuing People Support Team provide guidance on how to put the ideas into practice.

### ***Planning and assessment***

From the start, as pointed out above, it is important to know and understand local need and provide a range of options that meet those needs. In order to make these changes, short breaks should be given development priority within the department, as developing new approaches will require dedicated resources (both human and financial). Involving families and people with learning disabilities in this development process will ensure that the services produce user-friendly results.

Information about options, eligibility criteria and assessments need to be clear, concise, easily read, up to date and easily accessible. In particular, assessment processes need to be very transparent and care should be taken to ensure that people are aware of the level of service they can expect. People should be told their annual allocation so that they can plan ahead, and an independent brokerage system put in place to support the planning. In commissioning, the focus should be on outcomes- not just on providing the break but on what is expected out of the break. Joint audit and commissioning with health partners is recommended, and the suggestion made that commissioning with neighbouring local authorities may be beneficial. Connecting with other social, health and community services allows for a widening of opportunities for breaks.

### ***Funding***

Great emphasis is placed on ensuring that uses of funding are not limited – flexibility is key. If respite provision is all tied up in residential respite care, for example, then there is no flexibility to use the funding for other types of accommodation. There needs to be a funding pot which will enable flexible short breaks. It is also greatly beneficial to identify and work with providers with innovative ideas. The Valuing People short break guide provides examples of services which have sourced money from the following places:

- “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

The money has been spent through:

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

(Fitzpatrick & Wood 2007)

### **Choice**

As with funding, flexibility is key. Systems should be created which give people flexibility and control, such as point schemes, voucher schemes and direct payments.

- *Point schemes* – carers are allocated a number of points, based on assessment of need. These points have a monetary value and carers can spend their points on short breaks chosen from a menu offered by the Local Authority.
- *Direct Payments* - Where authorities allocate a number of nights respite to each carer, these can be translated into monetary value and offered as a direct payment.
- *Voucher Schemes* – Vouchers can be used at Local Authority provided services, although in some areas they can also be used by approved independent sector providers. The service user and carer can therefore use the vouchers as and when they want without going through social services. The Carers and Disabled Children Act of 2002 provides for local councils to deliver voucher schemes for short breaks.

### **Examples of approaches to short-breaks**

As stated earlier, there are a wide range of approaches to the provision of short breaks currently being used, with new ones emerging all the time. It is useful to

look at some examples and to see how they use the different parts of guidance outlined above.

### ***Midlothian Council – producing person-centred breaks***

In Midlothian the Local Authority worked with a respite steering group made up of service users and carers to explore people's needs from a short break. As a result of this, they started providing weekend or week long breaks with specialist hotel provision. They then developed a respite coordination service across all community care groups. Another focus has been on developing a systematic way of picking up on peoples' needs through the Single Shared Assessment and Carers' Assessment processes.

### ***Smart Breaks – brokerage service - Midlothian***

This has been quoted as best practice by a number of different bodies in England as well as Scotland. It is a short breaks brokerage service. They "use commitment to person centred planning to help and support people who have care needs to plan a more meaningful break. (They) work together with the disabled person and their families in a planning process to design a break that meets the individual's own interests and needs." (Fitzpatrick & Wood 2007) Working with service users and carers, they design breaks and options and provide information on possible sources of funding, helping with forms if necessary.

Other brokerage services are also being tried out as it is increasingly recognised that personalised planning of short breaks is very complicated. A model being used in Toronto, Canada, has a co-ordination service for the agencies and organisations providing respite service which people can contact directly for assistance in identifying the best respite option.

### ***Short Breaks Bureau – Perth & Kinross Council***

This is another type of detailed brokerage or "travel agency" service. Following assessment to work out the eligibility, a staff member of the Short Breaks Bureau will meet the family to explain what they do, how the breaks system works and what they will be doing next. They will then follow that up with another meeting to discuss the needs and wishes of the service user and their carers, what they want from the break, ideas they may have and what help and support may be needed. The Bureau will then look for holidays or breaks which will best suit the circumstances. Findings will then be presented back to the family where a final decision is made, dates are decided on and finances are arranged. Following the break, the Bureau will meet the family to carry out an assessment of their experience which can be built into their own breaks next time as well as to guide the experiences of others.

### ***Use of direct payments***

Using direct payments to pay for short breaks is an increasingly popular option, but requires the use of extensive support in order to plan a break which everyone is happy with. The types of brokerage services outlined above play a vital role here. The following examples of how direct payments can be used are provided by the Valuing People Support Team. One service user saved up her direct payment support to be able to pay for supported holidays and employment of a PA during those holidays as well as more regular community support to go to clubs and other activities. Another service user employs full-time carers every six weeks to go with him to the family's holiday home with his family, enabling them to spend time together without his parents acting as carers. In another case, the service user paid a volunteer's entrance and expenses to take him stock car racing twice a month, something he very much enjoyed but could not attend without help.

### ***Hotel in the Park, Tower Hamlets***

This is a hotel, where people with learning disabilities are guest rather than service users, taking a short break in their home city. This was born from the views of service users and carers who wanted breaks to be more like a holiday than any form of "care" service. The hotel is made up of seven en-suite rooms, two of which are completely adapted and include overhead tracking and hoists. All rooms have their own television and music centres and meals are prepared by a chef to be eaten in own rooms or in the dining hall. Guests are referred through social services and allocated a number of nights per year. Importantly, it has not cost the Local Authority anymore to run this service than a usual residential short break service.

### ***West Sussex Adult Placement Scheme***

This scheme supports people with learning difficulties to stay with individuals, couples or families for long or short periods of time. Twenty carers provide breaks for approximately 60 people. These breaks take different forms, with some involving the service user simply taking part in the activities of the carer's family, whilst others see the service user being fully supported to plan their own holiday activities, or using the stay as a B&B type service. There are a range of carers and facilities available to be able to provide for different needs. This is one of the Department of Health's Individual Budget pilot schemes.

### ***Natural Breaks – Merseyside***

This is a community based break, the focuses of which tend to be around particular community-based activities where people learn something new and meet new people. Natural Breaks works with those who have previously been considered too demanding of service providers to be given access to respite provision. In the "Social and Leisure" service of Natural Breaks, staff work with individuals who need one or more person to support them. They support the person with a disability to get out regularly and join in something such as college class, sports, voluntary work and evenings out. These outings are regular and frequent. The "Out and About" service sees a support work spending time with 3 individuals, enabling them to access leisure activities together.

### ***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 their families to take a tailor-made holiday together. Families can either bring their own supporters or have support provided for the holiday period. Part of the scheme is focused on training and supports people to learn independent living skills locally.

### ***Clayton Road short break centre, Newcastle upon Tyne***

This short break centre is focused on enabling people with learning disabilities to have a break in which they can relax, learn something new and live an "ordinary" life. "Everyone is different. We hope to make sure each person gets the kind of help they need." They encourage people to make their own decisions about how to spend their time whilst there, whilst being helped to make friends, learn things and be as independent as they want to be. There is an emphasis on service users having a say in how the centre is run.

### ***Emergency breaks***

Within the West Sussex Adult Placement Scheme mentioned above, one of the families is paid a retainer to accept people on an emergency basis if needed. There is also an in-house floating support service which can help in people's home

in an emergency and an older carers' worker who helps carers make plans for emergency situations.

The Sefton Carer's Centre has a Carers Emergency Respite Team which will provide an instant response in the case of an emergency which prevents a carer from continuing to care. Support can be provided up to a maximum of 48 hours, and further help will then be given to find more care if needed. This service includes an advance care planning component, which means that when a carer registers with the service they ensure that everyone is clear about what need and support would be needed in the case of an emergency.

### ***Breaks in Hertfordshire***

Hertfordshire has produced their own menu of short breaks. These include

- Four befriending schemes for people living with family carers.
- Activity schemes (where people go out in small groups evenings and weekends, etc), college breaks schemes,
- Help at home schemes.
- "Break away" schemes (i.e. holidays).
- A scheme where respite services go into homes to enable carers to take a break.
- A gym scheme, whereby people with learning disabilities access a mainstream gym, so giving carers a break.
- An arts workshop.

They have a "flexible pot" which can be used (up to approximately £500 per family) to provide anything that gives a family a break (e.g. holiday, weekly sitting service and so on).

## Conclusions

Central to the issues surrounding user-friendly provision of respite care is the concept of a break which benefits both carer and service user. The traditional approach to respite care, which saw the service user placed in residential care for a few days whilst the carer was "relieved of their burden", is outdated and in its place are innovative approaches to short breaks. These breaks should be designed by carers and service users with the assistance of local authorities, with the emphasis being on planning something useful, enjoyable and beneficial to **both parties**. Many different types of breaks are now being provided, including hotel type breaks, stay at home breaks, and daily community-based breaks.

In order to provide such a person-centred approach, a range of new systems are required which focus on ensuring flexibility of resources (financial and human) and maximising choice for service users and carers.

The delivery mechanisms for new models of short breaks can be multiple and varied, with the use of direct payments, vouchers or point systems leading the way in ensuring flexible options over which service users and carers have control.

To set these in place, local authorities need to carry out a full audit of available services, and work with stakeholders to identify what people want from short breaks.

Brokerage services are also key, especially in light of the increased use of direct payments to pay for short breaks.

Guidance on user-friendly respite is minimal, although the 2007 document issued by the Valuing People Support Team provides a much needed source.

Councils seem to be trying things out, experimenting somewhat, and in many cases are producing very innovative and successful models which could be built upon.

The Scottish Government seems to have gone a couple of stages further than their counterparts in putting together standards of care for respite which focus on the user experience, something which may emerge in the future for England and Wales.

In the meanwhile, the stage appears to be set for the development of new approaches, built upon the premise of flexibility and service user and carer involvement.

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