

OCCASIONAL PAPERS SERIES: MORE THAN A BREAK

No: 2 Date: March 2010

About

The purpose of our Occasional Papers is to promote (and provoke) new thinking around how we plan, deliver and produce better outcomes from short break services. Papers will focus on particular issues affecting people who use these services and their carers, but also the challenges facing service providers and those making strategic decisions. The papers can be downloaded from the Shared Care Scotland website and used freely for training and awareness raising purposes. For further information please contact Don Williamson at Shared Care Scotland.

More Than A Break

Introduction

The purpose of this discussion paper is to set out some of the key issues related to the experience of disabled children and their families in being able to access suitable short break and respite care support, and their experience of services received. The paper is intended as a starting point to stimulate a wider discussion amongst service users, carers, providers, planners and others to determine the main priorities for improving provision and achieving better outcomes for all concerned.

The paper has been written by members of the For Scotland's Disabled Children Task Group (FSDC) on Short Breaks. For further information on the FSDC campaign see: www.fsd.org.uk

The importance of short breaks

The importance of breaks from caring and respite care has been highlighted in many studies. Generally speaking respite care is viewed as a service which is provided to give the unpaid carer a rest from their caring responsibilities. This emphasis on the benefits to the carer has perhaps detracted from the equally important benefits that the break provides to the care recipient. Experience tells us that a successful break is more likely to be achieved when the support provided is designed to achieve good outcomes for everyone in the caring relationship.

It is important to stress that breaks should be viewed as a part of ordinary family life and relationships. We all need occasional time apart from those closest to us to pursue our own personal interests and to have a life of our own. We can then enjoy sharing these experiences when we come back together. Children and young people in particular benefit from occasional time away from their families to 'expand their horizons' and to develop the emotional, social and personal skills they will need to fulfill their potential as adults.

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Short breaks or respite care?

Traditionally the term 'respite care' has been used to define a break from caring, but this term is often associated with more institutional forms of service or hospital based stays. Despite the fact that most services have now moved on, this perception still exists. We therefore use the description 'short break' or 'a break from caring' within the paper, as we believe these are more acceptable descriptions. They imply the prospect of positive outcomes for everyone involved and shared benefits. Changing the language also challenges us to think more imaginatively about the many alternative ways people can be supported to have a break.

In 2008 the Scottish Government published updated guidance on the planning and development of personalised short break (respite care) services. The guidance states that:

'Short breaks are provided with the aim of enhancing and developing the quality of life of a person who has support needs and their carer (where there is one), and to support their relationship. The distinctive feature of short breaks is that they should be a positive experience for both. Short breaks can be provided within or out with an individual's home.'

The guidance provides examples of the wide variety of ways that short breaks can be offered, including:

- in specific short break units (specialist guest houses, community flats, purpose-built or adapted houses);
- breaks in care homes;
- breaks in the home of another individual or family who have been specially recruited (such as adult placement schemes, or fostering);
- breaks at home through a care attendant or sitting service (often short term but sometimes longer breaks);
- facilitated access to clubs, interest or activity groups;
- supported breaks in a chosen setting for the person with care needs either with or without their carer;
- befriending schemes where volunteers provide short breaks;
- peer support groups (e.g. for young carers);
- breaks in supported accommodation; and
- breaks using self-directed support

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

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Short breaks that meet the needs of disabled children, young people and their families

We propose that successful short breaks will have the following characteristics:

They will be:

- beneficial to children and young people by providing stimulating, fun and rewarding experiences, which support the following outcomes:
 - develop self-confidence and self-esteem
 - lead towards increased independence
 - offer opportunities to make and maintain friendships
 - help the development of social, personal and other life skills
 - promote good health and well-being
- child and young person centred - meeting their needs in a way which results in people feeling valued and included;
- flexible and responsive to the age and stage of development of the children and young people involved;
- family-centred - helping to strengthen and sustain family relationships, promoting family involvement in planning for breaks;
- inclusive - supporting children and young people to participate in their 'natural' peer groups and communities.

We also propose that:

- Children, young people and their families will be able to choose from a menu of short break options which reflect their different lives and priorities, which will change over time.
- Parents will be given short break support "right from the start" through the sensitive sharing of diagnosis and information, with the aim of providing a more personalised form of service.
- People will be helped through any age and service transitions to ensure continuous care and support.
- Each family will have access to a 'key worker' - a single point of contact through which support can be arranged and coordinated, and information, advice and support can be provided.

In summary, successful short break services will:

- be flexible and responsive to the whole family's needs
- be delivered by well-trained short break workers
- offer stimulating, fun and rewarding experiences
- be available at home and in the community
- ensure continuity of care
- be distinct from healthcare services
- provide the right support, in the right place at the right time

Obstacles to be overcome

We believe there are a number of obstacles which can prevent children, young people and their families from fully benefiting from the positive outcomes derived from short breaks:

- The limited choice and availability of suitable short break services
- Difficulties in sourcing information and advice about what services and support is available
- The prevalent, rather narrow definition of short breaks and respite care. (This should be widened beyond residential or family-based services to take account of the range of opportunities that non-disabled children and young people have access to, including: youth organisations, after school clubs, sports clubs, summer activity programmes, etc.)
- Services and support restricted to 'emergency relief' meaning families are not able to benefit from the preventative benefits of regular, planned short breaks.
- A general lack of consistency in the approach to a needs assessment, often dependant on the skill, empathy, knowledge and experience of the assessing worker(s)
- Poorly managed service transitions, particularly when moving from Children's to Adult services, often resulting in a loss of support at a critical time
- Lack of involvement with children, young people and their families in planning and preparing for their short breaks
- There are also specific challenges for disabled children affected by:
 - parental substance misuse
 - domestic abuse
 - parents with learning and/or physical disabilities
 - mental health issues
 - also young people themselves affected by their own poor mental health, substance misuse, criminal activity during adolescence
- Variable experiences in the quality of short break provision often linked to a lack of investment in staff training
- Children and young people who have a poor prognosis, or need more intensive support, are sometimes unable to access suitable services
- The prioritisation of resources (people and financial) within Children's Services towards child protection, and the impact of this on the development of other services, for example short breaks
- A lack of joined-up approaches across health, social care, education, housing and leisure services to deliver more integrated and flexible approaches to short break support
- The difficulties in reconciling the needs, wishes and expectations of the different people in the caring relationship

Short breaks as a human rights issue

Providing families with a break and giving children the opportunity to socialise and develop their personalities should not be optional for policy makers. In many cases, failure to provide these services undermines a family's dignity and well-being and violates their basic human rights. This is not only a moral issue, but also a legal one. The UK is bound by numerous UN human rights treaties that arguably support families' right to short breaks. These include:

The UN Convention on the Rights of Persons with Disabilities:

- Article 19: Persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services.
- Article 30: Countries are to guarantee that persons with disabilities have the opportunity to develop and utilize their creative potential not only for their own benefit, but also for the enrichment of society. Countries are to ensure their participation in mainstream and disability-specific sports

The UN Convention on the Rights of the Child:

- Article 15: Children also have the right to freedom of association and assembly. This means they are entitled to meet together and to join groups and organisations.
- Article 18: States should give appropriate assistance to parents and legal guardians in the performance of their child rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children. Further states shall take all appropriate measures to ensure that children of working parents have the right to benefit to childcare services and facilities for which they are eligible.
- Article 23: Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives.
- Article 31: Children have the right to relax and play, and to join in a wide range of cultural, artistic and other recreational activities.

The International Covenant on Economic Social and Cultural Rights:

- Article 10: The UK has a duty under this treaty to recognise that the widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children.

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Discussion questions

The purpose of this paper is to promote discussion and to generate feedback on the issues raised which can help to focus our efforts on the things that really matter to families. We would be very grateful to receive comments and ideas. The following questions may help you think about what you want to say. Share the paper with others to gain different perspectives.

Aspirations

- *Do our aspirations properly reflect what people need and want? Is there anything missing? Could we explain things more clearly?*

Barriers

- *Is our list of barriers or obstacles comprehensive? Are there any we've missed?*
- *What are the most important barriers we need to overcome? What do you think we need to do to address these?*
- *What can we do to support practitioners to take action?*

Rights

- *Should we be more active in using the UN Conventions and Treaties to argue for increased investment in short break services, or to protect families from service cuts?*
- *What rights would people like to see legislated for specifically in relation to short breaks and respite care?*

Feedback

If you have any comments or views on this paper we would be delighted to hear from you. Please contact us either at Shared Care Scotland (c/o don.williamson@sharedcarescotland.com) or through FSDC (c/o info@fsdc.org.uk).

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Other papers in this series

- Communication Breakdown

About Shared Care Scotland

Shared Care Scotland is a national charity which exists to support the development and improvement of short break services for carers and the people they care. Our services include:

- An online and telephone enquiry service to help put carers and service users in touch with short break services that best match their needs
- General information and advice on all matters relating to short break services
- Events, networks, publications and learning resources to share knowledge, experience and successful practice.

Please contact us if you require further information or advice.

w www.sharedcarescotland.org.uk
t: 01383 622462