

OCCASIONAL PAPERS SERIES: HOW ARE WE DOING? MEASURING SHORT BREAKS

No: 3 Date: January 2013

About

The purpose of our Occasional Papers series is to promote new thinking around how we plan and deliver better outcomes from short break services. Papers will consider different 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.

The topic of this paper is measuring the impact of short break services. The paper proposes a more systematic approach to the evaluation of short breaks to improve how future services are delivered. Examples of outcomes, performance indicators and data sources are provided, with links made to the national outcome frameworks to illustrate how these overlap.

The paper has been written with a particular focus on the planning and commissioning of short break services.

Measuring Impact

The importance of short breaks (respite care) to both unpaid carers and care recipients is well understood and has been highlighted again in recent national strategic developments including the Change Fund, Carer Information Strategies, the National Dementia Strategy and the Self-Directed Support Strategy. The 2010-15 Caring Together, Carers Strategy for Scotland (Scottish Government/COSLA) also asks specifically that local authorities, Health Boards and their partners:

“...consider how best they can support carers to have time-out from caring, and develop innovative solutions based on a better understanding of people’s different needs and circumstances.”



Significant additional resources are being provided to improve the support available to carers, including the availability of flexible, personalised breaks. The Change Fund for example will invest at least £46m over the next few years to give additional help to carers of older people, including we hope better access to short breaks. To ensure these resources are delivering the improvements expected, and to generate the evidence needed for longer term funding decisions, it is essential that effective measurement systems are in place from the outset.

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“The purpose of commissioning is to ensure that resources are used effectively to achieve policy aims and thus the best possible outcomes for people who use services. Although in practice much commissioning has focused simply on procurement, it needs to be a wider process that also strategically influences the way in which services are provided and the range of options available.”¹

Measuring the impact of short breaks services and evaluating their effectiveness will require new tools and techniques. Quantitative measures such as increased levels of service or increased numbers of people accessing services will continue to be important but they alone cannot provide the complete picture.

“For organisations, an outcomes approach can help to reconnect with their value base and ensure that they are focused on the difference they make to people’s lives, as well as the activities undertaken. Measuring outcomes is not enough in itself but can provide the ‘missing piece of the information jigsaw’ in relation to evaluating and improving services, and increasing accountability to the public and regulatory bodies.”²

Defining Short Breaks

In developing and implementing a performance measurement framework it is necessary to be clear what services and supports constitute short breaks and will therefore fall within the scope of the framework. These would generally include any services or practical support specifically arranged to benefit the carer(s) by providing a planned break from their normal caring responsibilities, and benefits the service user by providing opportunities to spend some time, independently of their normal carer, doing the things they enjoy. The period of time involved should be sufficient to allow both people a quality break. Having a break together, with the help of some additional support, can also achieve positive outcomes.

“The break might be for a couple of hours or for much longer. It might involve the cared-for person having a break away from home, thus benefitting the carer. Or the carer might have a break away with services being put in place to support the cared-for person. Some people may want to have a break together with additional support to make this happen.”³

¹ Short Breaks for Disabled Children, Briefing Papers Pack, National Development Team for Inclusion, Centre for Disability Research, 2011

² Measuring personal outcomes: Challenges and strategies. IRISS Insights, no.12, 2011

³ Caring Together, The Carers Strategy for Scotland, 2010-2015

The Scottish Government's 2008 guidance on planning personalised short breaks provides examples of different supports that can enable a break. The guidance states that a short break should be a 'positive experience for both', and that short breaks are effective in:

- helping carers to safeguard their health avoiding physical or emotional exhaustion, and enabling adult carers to continue caring; (While in the case of young carers, the overall aim is rather to prevent inappropriate levels of caring, short breaks have similar benefits of promoting health, wellbeing and social inclusion.)
- preventing social isolation - providing a break from their usual routine for people with care needs and carers, enabling them to take part in leisure or other activities;
- overcoming a crisis, such as the carer not coping, cared for person's health deteriorating, or bereavement;
- making time for carers to spend with family and friends; and,
- helping people (particularly those cared for by their parents) develop independence and prepare for the time when the carer cannot continue caring.

However, there is little evidence of systematic efforts by local authorities to measure whether the short breaks they are responsible for are effective in these areas. We hope this framework will serve as a useful starting point to address this issue.

Some of the proposed measures in this framework are more quantitative or activity focused, in order to gauge the 'extent' of service provision, others are concerned with the difference the short break experience makes to the people involved. (Note: It is important to distinguish between the outcomes that are developed at an individual level, for example in care planning, and outcomes that are developed for the purposes of overall performance measurement and ongoing improvement – such as those proposed in this paper.)

Measuring the quality and impact of short breaks depends on a genuine engagement with carers, service users and other key stakeholders, working together to determine what outcomes are people aspiring to, and what performance measures are appropriate and relevant to measure progress towards these.

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Further Guidance

If you have any questions please contact Don Williamson. Contact details can be found at the end of this paper.

Further background information has also been provided on our supporting web resource.

www.sharedcarescotland.org.uk/resources/Outcomes+Toolkit.htm

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Table 1a	
Relevant Scottish Government National Strategic Objective	
Promote a 'Healthier' Scotland through tackling inequalities; providing support for the elderly and tailored services for families and children; and supporting healthier, more active lives.	
Relevant National Outcomes	Relevant National Indicators
We live longer, healthier lives	Improve self assessed general health
We have improved the life chances for children, young people and families at risk	Improve mental wellbeing
We have tackled the significant inequalities in Scottish society	Improve end of life care
Our people are able to maintain their independence as they get older and are able to access appropriate support when they need it	Improve children's services
Our public services are high quality, continually improving, efficient and responsive to local people's needs	Improve support to people with care needs
	Reduce emergency admissions to hospital
	Improve the quality of the healthcare experience
	Improve people's perceptions of the quality of public services
	Improve people's perceptions of their neighborhood

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Table 1b Relevant National Outcomes for Community Care	Relevant Measures
Improved health	% of users and carers satisfied with their involvement in the design of care package.
Improved well-being	% of carers who feel supported and capable to continue their caring role
Improved social inclusion	% of community care service users feeling safe
Improved independence and responsibility	% of users satisfied with opportunities for social interaction
Table 1c: Relevant NHS Performance (HEAT) Targets	Relevant Targets
	<p>Reduce the rate of emergency inpatient bed days for people aged 75 and over per 1,000 population by at least 12% between 2009/10 and 2014/15.</p> <p>No people will wait more than 28 days to be discharged from hospital into a more appropriate care setting, once treatment is complete from April 2013, followed by a 14 day maximum wait from April 2015.</p>

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Comments on Table 1

These national performance frameworks are provided to show potential links and overlap with the short break outcomes and indicators proposed. It should be straightforward to make the connection between the outcomes and measures in Table 1, with those suggested for the short breaks and respite care in Table 2. Making these links will help local planners and service providers demonstrate how their work aligns with the wider strategic outcomes.

About the national frameworks

1a: There are currently 16 **National Outcomes** and 50 **National Indicators**. The above have been selected as being in our opinion the most relevant to short breaks/respite care but others may apply too.

1b: A suite of 16 underpinning measures has been developed with councils and NHS partners. From April 2008 these have been promoted as the 'gold standard' for evidencing improvement in relation to this (**Community Care**) indicator. The above have been selected as being in our opinion the most relevant but others may apply too.

1c: The **HEAT** Core Set are the key objectives, targets and measures that reflect Ministers' priorities for the Health portfolio. For 2012/13, 14 targets have been set out in the 'performance contract' between Scottish Government and NHS Board. There is an indirect but important relationship between the achievement of the NHS HEAT targets and the achievement of positive outcomes for carers. Carers can play a key role in supporting successful re-ablement and provide support to people with disabilities and long-term conditions to manage their lives as independently as possible. Supporting carers therefore helps contribute to these targets.

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Table 2a Suggested Local Outcome Measures	Suggested Local Indicators	Possible Data Sources
<p>Carers will feel supported by having timely access to a choice of appropriate short break services which are responsive to their needs and circumstances.</p> <p>Young carers will feel supported by having regular breaks from caring tasks to be able to enjoy activities with their friends, family or to have time for themselves.</p> <p>Service users will feel supported by having timely access to a choice of appropriate short break services which are responsive to their needs and circumstances.</p>	<p>Degree to which carers are reporting the short break services they receive have contributed to maintaining or improving their ability to have their own life outside caring and, where appropriate*, their capacity to continue caring.</p> <p>Degree to which carers are reporting they receive sufficient breaks to meet their needs.</p> <p>Degree to which carers and service users are reporting they are satisfied with the choice and quality of short break/respite care services available.</p> <p>Degree to which service users are reporting short break/respite care services have had a positive impact on their <i>quality of life</i>.</p>	<p>Locally designed surveys of carers and service users to take feedback – see Table 3</p> <p>Analysis of relevant sections in community care assessments for carer & service user - particularly at the review stage.</p> <p>Reports from inspectorates and other agencies including Care Inspectorate and local carer and disability organisations.</p>
<p>Ideas for improvement targets: develop service feedback and evaluation systems for local monitoring and benchmark year 1, aim for % improvement in satisfaction levels from year 2 on. Sampling may be appropriate. *It is not appropriate to expect short breaks to sustain young carers in a caring role.</p> <p><i>Quality of life indicators:</i> physical, mental and emotional health, sense of well-being, confidence and safety, improved opportunities for social inclusion and the ability to live as independently as possible. For children and young people, reference should be made to the national Getting it Right for Every Child framework.</p> <p>There are a range of ‘tools’ that can be used to measure quality of life outcomes – see Table 3 for examples.</p>		

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Comments on Table 2a

It is important to take data from a range of places rather than rely on one source. Outcomes for carers and service users may need to be measured separately. Clients should be able to give feedback **anonymously** if they choose, and perhaps via an **independent advocacy organisation**. **Validate results** by comparing to any statutory service inspections or through **sampling** or **focus group** activities.

It is vitally important to make every effort to reach carers that are perhaps outside the usual networks and therefore unaware of the support that may be available to them – i.e. carers who may not be currently accessing a service.

Shared Care Scotland together and partners have produced a questionnaire which has been used to carry out a national postal survey of short breaks/respite care along with a focus group discussion prompt. This could be adapted for local survey exercises. <http://www.sharedcarescotland.org.uk/resources/Outcomes+Toolkit.htm>

Surveys or other forms of gathering feedback will need to be **tailored** to the group being consulted and their communication needs. Gathering feedback from people with reduced levels of communication and younger children can be supported, for example, by using arts and crafts type activities, graphic facilitation, video recording, etc.

In many cases of course it will be difficult - and unrealistic - to credit short breaks alone as the single contributory factor that produces improved outcomes for carers or service users. Determining the '**attributability**' of different interventions is a complex area that requires careful consideration before making ambitious claims! Greater levels of joint planning with other services on measuring outcomes will contribute to a better understanding of how outcomes can be enhanced by working together.

As well as surveying carers and service users, it is essential too that **service providers** are also surveyed periodically to gain their perspective on service quality and to anticipate any future difficulties which may affect their capacity to deliver good outcomes in a sustainable way.

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Table 2b Suggested Local Outcome Measures	Suggested Local Indicators	Possible Data Sources
<p>Carers will feel supported by having timely access to a choice of appropriate short break services which are responsive to their needs and circumstances.</p> <p>Young carers will feel supported by having regular breaks from caring tasks to be able to enjoy activities with their friends, family or to have time for themselves.</p> <p>Service users will feel supported through timely access to a choice of appropriate short break services which are responsive to their needs and circumstances.</p>	<p>Proportion of carers/service users receiving support to take a break measured against the total number known to the local authority.</p>	<p>Census or Scottish Household Survey (SHS) information on nos. of carers and hours of caring provided. 2001 Census figures available for total no. of people providing unpaid care, unpaid care 1-19hrs, 20-49hrs and 50+ hrs.</p> <p>Census/SHS information on ethnicity of carers/s.users.</p> <p>Local registers of care recipient/carer groups – analysis of other data sources e.g. DLA recipients, disabled children with Additional Support Needs etc.</p> <p>Locally collected information on nos. receiving short break services per care group and ethnic profile compared against total numbers of carers known.</p>
<p>Ideas for improvement targets: set annual target % increase for nos. of carers/s.users receiving short break services against known nos. of carers/s.users. Targets can be set for each client/care groups. Services to minority ethnic carer /s.user population should also be carefully monitored and also other groups that are known to experience greater challenges in accessing appropriate services.</p>		

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Comments on Table 2b

Services may be targeted at highest priority groups, i.e. those caring 20+ hours a week. However it is important that support is determined by assessment/review as some carers caring less hours may still be at high risk. Comparing the number of carers receiving services to the total number of carers (perhaps within 50hrs+ & 20hrs+ groups) will give an indication of the 'reach' of services.

Public bodies must also be aware of their duties in relation to the Equality Act 2010 to 'advance equality' and to have a clear understanding of how commissioning decisions may impact on equality outcomes.

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Table 2c: Suggested Local Outcome Measures	Suggested Local Indicators	Possible Data Sources
<p>Carers will feel supported and better able to continue their caring role through timely access to a choice of short break services which are responsive to their needs and circumstances.</p> <p>Young carers will feel supported by having regular breaks from caring tasks to be able to enjoy activities with their friends, family or to have time for themselves.</p> <p>Service users will feel supported through timely access to a choice of short break services which are responsive to their needs and circumstances.</p>	<p>Evidence of increasing volume and choice of breaks.</p> <p>Evidence of decreasing levels of recorded unmet demand.</p> <p>Evidence of cost effectiveness and/or Social Return on Investment</p>	<p>Scottish Government figures on local authority respite: total overnight respite nights provided; % overnight respite nights not in a care home; total hours daytime respite provided; % daytime respite hours provided not in a day care setting.</p> <p>Carer and service user feedback – see Table 3</p> <p>Local cost/benefit analysis of usage and costs of existing services against outcomes/outputs delivered & levels of service user satisfaction.</p> <p>Increasing access to short breaks via Self directed Support (SDS)</p> <p>Information from carer/care assessments on service gaps and/or unmet demand.</p> <p>Reviews of carer /respite care strategies and action plans.</p>
<p>Ideas for improvement targets: % increase in volume of breaks provided. % increase in breaks provided not in a care home or day care setting. % increase in carers responding positively to ‘appropriateness’ of service received. % increase in service users using different forms of SDS to access short breaks.</p>		

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Comments on Table 2c

Some of the data collection in this section will relate to the data collected by the Scottish Government to measure progress towards/maintenance of the additional 10,000 weeks of respite care across Scotland. Local improvement targets will be needed.

The proposed local indicators also relate to the 2008 Scottish Government Guidance on Personalised Respite Care. This aims to improve respite planning, shift the balance of care towards preventative action, and promote more personalised methods of support.

A distinction can be drawn between unmet need and unmet demand where the latter is restricted to cases where a need is identified, through an assessment for example, but cannot be met. Also simply measuring assessed demand may only identify demand for traditional or known types of services and efforts may be needed to explain to people wider options which may be a better match to the identified outcomes.

It is important to distinguish between planned respite care provision and emergency or crisis support. Support provided for emergency situations would not generally be regarded as respite as the intended outcomes would be different, i.e. there may be little choice, flexibility or control over the service provided. A separate outcome and indicator which relates to the existence of, and level of satisfaction with, an Emergency Replacement Care Plan would perhaps be appropriate.

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Table 3 Some Tools for Measuring Outcomes	When It's Going Well
<p>Surveys of carer/service user satisfaction with respite care services received should include questions which produce feedback on all aspects of the service, from the initial stages of assessment, information gathering and planning, to the experience of the service, the follow-up and impact.</p>	<p>Carers and service users are very satisfied with the choice and affordability of the short break services available to them.</p>
<p>The column on the right provides guidance on the areas that should be addressed when evaluating services from a carer/service user centred perspective. The feedback will be largely qualitative. The topics have been identified by carers and service users as key determinants of effective services.</p>	<p>Carers and service users are very satisfied with their involvement in planning and reviewing their short break.</p>
<p>Shared Care Scotland has also developed a Short Breaks Feedback Form (Better for the Break) which can be used with carers and service users to take feedback on their experience of short breaks. www.sharedcarescotland.org.uk/resources/Outcomes+Toolkit.htm</p>	<p>Carers and service users are very satisfied with the frequency, length and reliability of the short breaks they received.</p>
<p>The Talking Points Toolkit has been developed to enable health and social care partnerships to gather data to determine whether they are delivering good outcomes to service users and carers. This data can be used to include user and carer experiences in performance management, planning, commissioning and service improvement. Further information on Talking Points can be found at: www.sharedcarescotland.org.uk/resources/Outcomes+Toolkit.htm</p>	<p>Carers and service users are very satisfied with the suitability and quality of the short break services they received.</p>
<p>Other tools such as The Rickter Scale or SHANNARI (Getting it Right for Every Child) well being indicators may also provide effective ways of measuring individual outcomes.</p>	<p>Carers and service users are very satisfied with how information is promoted including any eligibility criteria and what short break options are available.</p>
<p>The Evaluation Support Scotland website is another source of advice and information on outcome evaluation. www.evaluationsupportscotland.org.uk</p>	

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Table 4

Good Practice Example of Service User Participation in Outcome-Based Commissioning - © Together for Disabled Children, November 2010

The active participation of disabled children and young people has been a key feature of the development of short breaks in the London Borough of Redbridge. Participation has included creating a commissioning panel of children and young people in parallel with the (adult) commissioning group. The young commissioners have provided input to the providers' forum, evaluated tenders and provided evaluation of the services they have received.

As part of the Redbridge tendering process providers were requested to submit a separate, child-friendly version of the tender. This version was evaluated and scored by a dedicated children and young people's commissioning panel, which gave feedback to the overall commissioning group. The children and young people's scores made up 10% of the overall score. The requirement for a child-friendly version of the tender documents has been very revealing. Some bidders clearly had difficulty producing something meaningful and as a consequence the children and young people's panel rejected these.

The panel also gave approval to bids for short breaks that offered activities that would give them new challenges and experiences. Their preferences were orientated to adventure type activities – sailing, climbing, abseiling etc. and doing things that other young people do, for example through befriending projects. They rejected some of the more tried and tested models of 'safer' short break provision because they wanted something different.

The involvement of the children and young people in this way has been very influential. Some of the outcomes of their evaluation of bids came as a surprise to the adult commissioning panel and has improved their understanding of the children and young people's wishes and aspirations. As a consequence money was spent on services that the children and young people really wanted.

It worked because children and young people:

- were given a genuine role in the process
- experienced the effect of their participation in the commissioning process

They were shown respect and active participation and self-determination have been modeled to the children and young people, their parents and to professionals. The participation of children and young people is now embedded in the commissioning process.

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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
- Administration of the Short Breaks Fund to support Third Sector organisations to develop flexible, personalised and imaginative short break services

Please contact us if you require further information or advice.

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