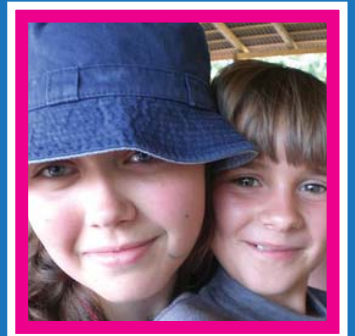
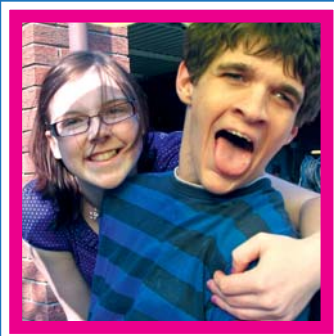




# SHARED CARE

scotland

## It's about time: An overview of short break (respite care) planning and provision in Scotland



Short Breaks mean everything to our family. They give us the ability to recharge our batteries and carry on

**SHORT BREAK (RESPITE CARE)  
PLANNING AND PROVISION IN SCOTLAND**

**REID - HOWIE ASSOCIATES LTD.**



**A Report for Shared Care Scotland  
November 2010**

## **Foreword**

'It's about time' provides an overview of how local authorities in Scotland are approaching the planning of short break and respite care services. The research, carried out for us by Reid-Howie Associates Ltd, focuses on planning and provision within Adult and Older People's Services. Shared Care Scotland is also working with For Scotland's Disabled Children (FSDC) to gather similar information on provision within Children's Services and this will be published separately by FSDC at a later date.

Not unexpectedly, the report identifies different attitudes and approaches to service planning and varying levels of provision across the country. Differences are revealed in the levels of respite care across age and care groups, the amount of 'effort' being expended on developing systematic, strategic approaches to service planning, the pace of progress towards the personalisation of short breaks and, at a basic level, differences in how respite is defined and measured. All contribute to producing a rather unequal picture of respite service provision for unpaid carers across Scotland in 2010. The report points out that this variation cannot be fully explained, or justified, by demographic or geographic factors, or by people in different areas simply expressing different needs or preferences.

On the plus side, the report highlights shared views around the continuing importance of short breaks in promoting health and sustaining caring relationships, an awareness of the benefits of early intervention and the need to give carers and care recipients more control over how, where and when short breaks are provided. The further development of brokerage services is picked out specifically as an example of innovative practice which could help to deliver these outcomes. There is also recognition, amongst those interviewed at least, that carers do play a vital role in underpinning the delivery of statutory services, and consequently should be more closely involved in service commissioning decisions.

However, the key message we hope people will take from the publication of this report is that more can and must be done. Particularly in these difficult times, increased local effort is needed to ensure we are using all the available resources to achieve the best possible outcomes. This is a time for creative thinking, joined-up planning, new partnerships and strong and sustained leadership around this issue. Those who depend on quality short breaks will no doubt respond, *'It's about time'*.

**Don Williamson**

**Shared Care Scotland**

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- Particular thanks go to the researchers and authors of the report, Dr Brian Henderson and Dr Sheila Reid of Reid-Howie Associates Ltd.

## **About Shared Care Scotland**

Shared Care Scotland exists to support and promote the development of good practice in short breaks and respite care, and to improve access to information and advice. Our annual programme of events includes short courses, road show events, practitioner and service user exchange forums, a biennial conference and online discussion forums.

Our services include:

- An online directory and telephone enquiry service to help carers and service users find short break and respite 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.

You'll find further information on all these services throughout our website:  
[www.sharedcarescotland.org.uk](http://www.sharedcarescotland.org.uk).

We are also very happy to contribute to external events and have lots of experience of running workshops and delivering presentations to wide ranging audiences.

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## **EXECUTIVE SUMMARY**

This report presents the findings of research carried out between April and August 2010 to: improve knowledge and understanding of the landscape of respite care and short break provision for adults in Scotland; identify good practice in the planning, commissioning and design of respite care and short break services; and better understand the challenges and identify solutions to moving towards more flexible, personalised respite care and short break services for adults.

The research focused on the views of stakeholders in the public sector, although a number of carers' and other organisations also contributed views. This research did not set out to be an evaluation of short break provision and the views of both carers and cared for people may be different to those set out in this report.

### **The local policy context**

There was found to be considerable variation both in the strategic context for short breaks and the ways in which these were managed. Local structures were found to be varied, although common elements were high levels of partnership working and that the main locus of responsibility for delivery rested with social work departments (or merged social care departments where these existed). The involvement of the NHS in the delivery of short breaks was found to be minimal.

The overall strategic context for short breaks was generally set by Single Outcome Agreements, Community Plans, Joint Community Care Plans or similar. Relatively few areas were found to have created specific Short Break Strategies, although some were considering this. In a majority of cases, policy relating to short breaks was contained within carers' strategies and strategies relating to individual client groups, either singly or in combination. NHS Carer Information Strategies generally did not refer to short breaks directly, although some elements of delivery were likely to have an impact on the identification of hidden carers.

Some concerns were expressed about difficulties which might be created through the lack of a short breaks specific strategic context, particularly where partnerships were seeking to establish the effectiveness of their provision or when reassessing the balance of community care provision in the light of budgetary pressures.

Although not a specific focus of the research, a high level of engagement of the voluntary sector (both relating to carers and cared for persons) was noted. This engagement was generally at both a strategic and an operational level, and was most commonly formalised through various forms of working group structure.

Strategies relevant to short breaks (regardless of their focus) were generally created either in partnership with, or in consultation with both carers and cared for persons. Engagement with service providers at a strategic level was found to be more limited, although there was generally a high level of contact in relation to operational matters.

The research found a high level of agreement about the purpose and value of short breaks, and these were consistent with those set out in the current National Guidance. There were, however, variations of view about what could be considered

to be a short break, and these differences were also found to have an impact on measurement both of volume and outcomes.

There was a clear view that unmet need was difficult to identify and measure, and that the main method for measuring demand was through the aggregation of assessments. A variety of means were noted by which local authorities, generally in conjunction with carers' organisations, had tried to engage with hidden carers, and through this, identify unmet need, but these were found to have had limited success.

### **Delivery issues**

The delivery of short breaks was also found to vary considerably across Scotland. The basic process of assessment was found to be broadly similar, although the nature of the techniques used, and the means of carrying out regular reviews, did vary.

In relation specifically to the identification of the need for a short break, a number of concerns were raised about the extent to which the likely outcome depended on the view of the assessor. Similarly, the way in which these needs were satisfied also, in most cases, depended on the knowledge, perceptions and experience of the assessor. One consequence of this, raised by a variety of participants, was a perceived over reliance on "traditional" forms of short break, even where options better suited to the needs and wishes of both the cared for person and carer existed.

Variations were found in approval processes, although no issues were raised in relation to this. In virtually all cases, the number of nights or weeks available to a cared for person was decided as part of the assessment, although generally within limits imposed by the local authority. The nature of these limits was found to be highly variable, and there was evidence of these being reduced in response to budgetary pressures. Some local authorities imposed budgetary limits, although it was generally open to the recipient to find other sources to meet the whole cost.

Some evidence was identified of local authorities changing the prioritisation threshold for receipt of a short break, for example, to make it unlikely that someone assessed as having a moderate or substantial need would be able to access a short break. It was suggested that this was being done to help manage reducing budgets.

Although not a specific focus of this work, the issue of charging policies was raised by a number of participants. The basic issue identified was these appeared to vary across Scotland, and could act as a disincentive to some to seek, or take up a short break.

Personalisation was found to be a key focus of the work of most local authorities, although the pace of change was variable. A number of elements of personalisation were identified, including improvements in assessments (with a heightened focus on outcomes), more use of Self Directed Support, the development of Short Breaks Bureaux and, most fundamentally, a move away from block towards spot purchasing.

There was evidence of some local authorities developing options which were more flexible, and which were perceived to deliver better outcomes, even though the



number of nights or weeks awarded was lower. Examples of this generally involved the cared for person and carer taking a break as a family, often in a mainstream holiday setting, with additional support being purchased where required.

Many local authorities noted a focus on preventing both carer breakdown and admission either to hospital or long term care. A number of aspects of this were identified, including improved assessments, the use of regular reviews, telecare and the delivery of mainstream services.

There was found to be a particular focus across a number of local authorities on improvements to assessment and review process, and particularly on the identification of client-specific outcomes. However, it was clear that most were facing difficulties in finding consistent and meaningful ways of both expressing and measuring these.

Although there was a general view that carer assessments were a good thing, local authorities had had mixed success in rolling these out. In some areas, take up remained relatively low. Some carers' organisations have been given the right to carry out carer assessments on behalf of the local authority.

Few issues were identified with emergency or crisis support where this was required, and local authorities appeared able to cope with peaks in demand. Much of the work set out earlier in relation to general preventative measures was also found to impact on reducing the likelihood of the need for emergency or crisis support.

A small number of areas had invested in Short Breaks Bureaux. A number of advantages were identified for these, including that the centralisation of information and the concentration of expertise in the identification and booking of both traditional and non-traditional options would both take pressure off front line staff and lead to better options for clients. The main concerns expressed about Short Breaks Bureaux related to establishment and running cost, and the lack of an evidence base for both costs and benefits.

There was some evidence of increases in the use of Self Directed Support (SDS) to purchase more appropriate, non-traditional breaks. However, the numbers receiving SDS and direct payments was low. There was evidence of some SDS support services developing services akin to Short Breaks Bureaux to meet the needs of this client group. However, a number of difficulties with using SDS for short breaks were identified, including a lack of awareness on the part of care managers, technical issues with payment methods and accounting practices, and the fact that, in some areas, this group may not have access to specific support.

Increasing use of telecare was identified, in some cases, to help provide a short break for carers. Views of telecare were mixed, although it was suggested that it can contribute both to increased efficiency and delaying the admission to long term care when used as part of a basket of services.

### **Demand issues and provision to specific groups**

Most local authorities believed that most expressed demand for short breaks was currently being satisfied although there were considerable variations by client group

and locality. Few waiting lists were identified, although in some areas and for some client groups, it may be difficult to provide breaks at the time and in the location preferred.

Local authorities with significant rural areas identified difficulties arising from both the distances involved and the mix of provision available. Some examples were identified of community – based provision as a way of helping to overcome these difficulties.

A wide range of issues were identified with the transition between children's and adult services, largely as a result of both the change in eligibility for services, and the pressures falling on families due to reductions in the level of services available. Most local authorities identified that steps were being taken to ameliorate these issues as far as possible, but there was limited evidence of information sharing across local authorities.

Some issues were also identified with the transition between adult and older people's services, again relating to changing eligibility and the requirement in some cases for cared for persons to attend services they did not perceive to be suitable to their needs or wishes. Again, examples were identified of ways in which local authorities had adapted processes, or used flexibilities in budgets to overcome these issues.

There was no consistent pattern of provision to individual client groups across Scotland. In part, this may be due to variations in recording practices, but may also reflect different priorities in local areas. The extent of the variations, however, in relation to overall weeks delivered to both adults or older people was significant.

The most common forms of provision for people with physical and sensory impairments were: in-home short breaks provided by an external service; overnight short breaks in a specialist facility; overnight short breaks in a care home or residential setting and independent short breaks e.g. at a B&B or hotel. Some examples were identified of services catering for specific client groups, but many concerns were also expressed about younger disabled people having limited choices in relation to short breaks, particularly in areas where a care home bed may be the only option. This group was also considered most likely to face longer waiting times and less choice of location. A number of examples were noted of people with physical and sensory impairments using innovative approaches in relation to short breaks, generally to allow families to holiday together.

The most common forms of provision identified for adults with learning difficulties were: in-home short breaks; overnight short breaks in a specialist facility; independent short breaks; and day short breaks via volunteers or support services. There was evidence that provision was not uniform with, for example, specialist residential units existing in only a limited number of areas. Where no specialist provision existed, use was generally made of either block or spot purchase arrangements to source provision in other areas. Relatively few specific issues were identified in relation to provision for this group, although it was recognised that they could face some barriers. There was little evidence of significant delays or constrained choices. As with people with physical and sensory impairments, a number of examples of innovation in relation to non-traditional types of short breaks were identified.

The main forms of provision identified for older people were: in-home short breaks; residential breaks in a care home; and day centres. Older people were seen as most likely to actively prefer a traditional care home setting. More widely, it was suggested that this group was likely to have the highest levels of unmet need. Some local authorities had tried to move away from “traditional” overnight short breaks, partly by identifying alternatives and partly by seeking to educate both care managers and service users, as well as their carers. It was suggested that these efforts had not always been fully successful. There were a small number of examples of overnight provision for older people away from care homes but this group was the least likely to demonstrate innovation. There was evidence of significant increases in the use of telecare for this client group. Increasingly, services were found which had been created in response to the needs of older people with dementia, although a wide variety of issues and difficulties were identified, both for carers and service users, and for service providers.

The main focus of provision identified for people experiencing mental health problems was: specialist day services; flexible breaks with support; breaks at centres run by national voluntary organisations or flats managed locally and some home-based short breaks. Generally, this group was seen as most likely to experience barriers to accessing short breaks. In addition, this group was also seen to be the least likely to request, or take up short breaks, with some raising questions about the suitability of short breaks. A small number of examples of innovative approaches were identified, but these were uncommon.

Although there was some recognition of issues for ethnic minority clients and carers, it was also clear that they may be likely to face a wide variety of barriers in both finding out about, and gaining access to services. Some local authorities were found to have done little to identify or meet the needs of these groups. Most examples of specific provision were found in cities, and in surrounding local authority areas. There was only limited evidence of Equality Impact Assessments being used in relation to short breaks for ethnic minority clients.

### **Suggestions for action**

A range of suggestions for further action were made, including the following<sup>1</sup>:

- The Scottish Government and CoSLA should consider re-promoting the national guidance with a view to increasing the take up of at least the option of the development of a position statement about short breaks in each area.
- The Scottish Government and CoSLA should review whether the current national guidance is adequate in ensuring that carers and cared for persons have broadly equal access to services regardless of their home location. Allied to this, it is suggested that CoSLA’s annual guidance on charging should encourage greater consistency between councils.
- The Scottish Government should consider periodic monitoring of the nature, application and consistency of the criteria used by individual authorities for deciding whether or not to offer a short break to a service user.

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<sup>1</sup> These have been presented in a summarised form. The suggestions in full can be found in Section 6 of the main report.

- Two linked pieces of work should be considered to develop cost benefit analyses: a general piece of work to consider the costs and benefits of short breaks and benchmark these against other forms of social care; and a specific piece of work to consider the costs and benefits of Short Breaks Bureau-type arrangements in delivering both outcome-focussed and personalised provision
- Shared Care Scotland should convene a small group to bring together non-statutory good practice guidance on ways to identify unmet need (viewed from the perspectives of both carers and cared for persons), and beyond this, on means of engaging with hidden carers. In this context, it would make sense for the NHS to be represented on this group, given the focus on these issues within Carer Information Strategies, as well as the Scottish Government's Joint Improvement Team.
- If the Scottish Government decides to extend eligibility for community care services to carers in their own right, it is suggested that consideration should be given to providing guidance on how eligibility and prioritisation criteria should be developed in order to avoid the potential issue that many carers who are assessed as requiring a service may not be able to access this as they do not achieve a high enough prioritisation when judged against other categories of service user.
- A short guidance note is prepared specifically on the use of Equality Impact Assessments (EQIAs) in relation to short breaks and associated support services.
- Local authorities should be asked to report on the carrying out of EQIAs in relation to short breaks (with any consequent actions arising from these) as part of Scottish Government's monitoring processes.
- A short life working group could be convened to consider the range of outcome and review tools available to local authorities (such as the commonly used method Talking Points) and develop guidance on how to use these effectively, for example, in relation to user training, the choice of specific criteria to be used and the frequency of reviews.
- Good practice examples from local authorities should be gathered and published as a means of highlighting innovation and helping develop consistent practice across Scotland.
- National carers' organisations should gather and publish good practice examples arising from local carers' organisations being able to undertake assessments. As part of this, it is suggested that some guidance should be included on how to ensure that these third party assessments can be fully incorporated into local authority decision making and management processes and, more directly, be afforded the same weight as if they had been undertaken by a care manager.
- A small piece of research could be commissioned to investigate the extent to which carers are satisfied with the assessment process, and the extent to which a positive assessment leads to the delivery of a service (whether by a local authority or voluntary organisation).
- As part of the annual returns process, local authorities should be asked to provide data on the number of carers offered assessments, and the number of carers choosing to take up the opportunity.
- Work should be undertaken to update common definitions and measurement categories, building on those in the national guidance. This should address

issues such as the circumstances in which home care or attendance at a day centre could be considered to be respite (e.g. where the period of service exceeds a time threshold or where it is identified in a care plan), and whether (and if so, how), the impact of telecare could be reflected in national statistics.

- Related to this, work could also be undertaken to develop guidance to local authorities about how to measure and report on short breaks taken by those managing their own care package using Self Directed Support.
- As part of the development of better definitions and measurement categories, the Scottish Government should develop guidance on how best to capture equality information about beneficiaries (and by extension, carers). Particular regard should be paid to people who fall into more than one group.
- The Scottish Government should consider whether future data gathered could better disaggregate different forms of provision.
- Work could be undertaken at a national level, but involving local authorities, the Scottish Government and others, to help develop a standardised approach to the identification and use of outcomes, as well as guidance on appropriate forms of measurement. Clearly this would impact on national, as well as local reporting arrangements. The work currently being facilitated by Shared Care Scotland in relation to a common evaluation framework could both inform and be informed by this work.
- In relation to the concept of shared benefit, Shared Care Scotland could convene a short life working group of, for example, national carers' organisations, Independent Living in Scotland, Age Scotland and the Long Term Conditions Alliance to produce guidance both on how to ensure that local strategies and policies reflect issues for carers *and* service users, and to advise on the development of outcomes which would be effective for both groups.
- As part of this, it could be helpful for such a group to develop a practice guidance note for assessors to help them deal with situations where the views of carers and the cared for persons are at odds.
- Shared Care Scotland could (with the assistance of, for example, ADSW) develop a practice guidance note for social work staff focusing on up to date thinking on short break options.
- It is also suggested that local authorities should be encouraged to build on work done by Shared Care Scotland and individual social work departments to build awareness raising about short break options into continuing professional development programmes.
- Local authorities should be encouraged to contribute to, and make use of the new online directory of short break opportunities developed by Shared Care Scotland. At a local level, promotion of the directory to individual social workers should be undertaken as a way of encouraging consideration of less traditional short breaks options.
- Self Directed Support Scotland and the local authority SDS network should jointly produce a good practice guidance note for both voluntary and public sector support services on short breaks. Such a note could then be used to benchmark and, if necessary, develop services for people using SDS to fund short breaks.
- Shared Care Scotland, as part of its programme of conferences and workshops, should consider an event bringing together organisations from each of the interest groups with a view to identifying areas of common

interest, and potentially, a sustainable forum through which mutually relevant issues could continue to be discussed.

- A short life multi-agency working group, involving carer and client groups, as well as both local authorities and health services, could be convened to review emerging practice and ideally develop good practice guidance in managing the transition between children's and adult services.
- Consideration should be given to how to address issues relating to short breaks for ethnic minority clients and carers, for example, through the development of guidance, staff development resources or through encouraging the use of the Equality Impact Assessment process.

# SECTION 1: BACKGROUND AND CONTEXT

## Introduction

1.1 This report presents the findings of research carried out by Reid Howie Associates for Shared Care Scotland between April and August 2010. The overall aims of the research were to:

- Improve knowledge and understanding of the landscape of respite care and short break provision for adults<sup>2</sup> in Scotland.
- Identify good practice in the planning, commissioning and design of respite care and short break services which leads to better outcomes for carers and the people who use services.
- Better understand the challenges and identify solutions to moving towards more flexible, personalised respite care and short break services for adults.

1.2 The focus of this work has been on the views of stakeholders in the public sector. The focus is deliberate. Local authorities<sup>3</sup> are responsible for the funding of virtually all short breaks. Through both care homes and specialist services, local authorities are also responsible for the delivery of a significant proportion of the short breaks taken in Scotland. Evidence from carers' organisations suggests that much of the data gathered about the views of carers during the Care 21 process remains valid. This data has been used in preference to carrying out further primary research with carers.

1.3 This research did not set out to be an evaluation of short break provision and it is important to bear in mind that the views of both carers and cared for people may be different to those set out in this report.

1.4 It is important to bear in mind that this research was undertaken in the period April to June 2010. Potential cuts in funding were clearly being considered by local authorities at that time (and are referred to in the text), but the likely scale of the reductions only became clear after the research was completed. The conclusions and recommendations can only reflect the funding position at the time the research was being undertaken.

## Overview of methodology

1.5 The main elements of the methodology are summarised briefly below and involved:

- A review of relevant literature.
- Interviews with nominated interviewees covering all 32 local authority areas.
- Interviews with representatives of 9 NHS Boards.
- A survey of statistical information (16 responses).

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<sup>2</sup> A separate piece of research was commissioned to consider issues for young people.

<sup>3</sup> It is acknowledged that, in some areas, functions of local authorities and NHS boards have been merged. However, for the sake of clarity, the term "local authority" is used throughout this report but should be taken to include merged social care services.

- Discussions with carers' organisations, independent living organisations and services supporting people using Self Directed Support.

1.6 The work was overseen by an Advisory Group drawn from both carers' organisations and local authorities. The group commented on the research methodology and tools, provided advice on accessing information and commented on both the findings and recommendations.

## **The report**

1.7 The report is in 6 sections. The first provides an overview of the research, as well as the broad policy context. Section 2 provides an overview of the local policy context, including a summary of the ways in which planning is undertaken, and engagement with carers and the voluntary sector. Section 3 provides a summary of local delivery issues, including an overview of general policy issues. Section 4 covers issues relating to demand, as well as and an assessment of the some of the issues pertinent to, for example, rural areas and different groups of service users and their carers. Section 5 presents some key conclusions, while the final section offers suggestions for further action.

1.8 With the exception of direct quotes from published material, all of the findings of this research are presented anonymously. If readers require further details about any of the examples provided, they should, in the first instance, contact Shared Care Scotland.

## **Short breaks**

1.9 The focus of this research is on short breaks, and "short breaks" will be defined in detail later in this section. Essentially, this means "a carer and the person they care for being supported to have a valuable break from the normal routine and demands of their caring situation. People without a carer can also benefit from a break from their home circumstances."<sup>4</sup> Before describing this in more detail, however, it is useful to outline both the social care relationship and national policy context.

## **The social care relationship**

1.10 From a policy perspective, a social care relationship involves at least two parties: the carer and the cared-for person.

## **Carers**

1.11 Social care is provided by two main groups.

1.12 The first is a paid workforce, many of whom work for local authorities or voluntary organisations, and increasingly for individuals using direct payments to manage their own care. The paid workforce is large, among the largest single sectors in Scotland, and growing. However, the paid workforce is not a specific focus of this research.

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<sup>4</sup> Extracted from "What is meant by short break (respite) care?" (Shared Care Scotland, 2009)



1.13 The second group involved in providing social care is unpaid carers. This report adopts the Care 21 definition of “unpaid carers”:

*“the term ‘unpaid carer’ is used to describe individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system e.g. carers allowance.”*  
(p4)

1.14 The main focus of this report is on unpaid carers.

1.15 There is no definitive figure for the number of unpaid carers in Scotland or the UK. In part, this is as a result of the fact that many people, although having caring responsibilities, do not recognise themselves, and certainly would not describe themselves as carers. Current government estimates suggest that as many as 1 in 8 adults, and a smaller, although still significant number of children and young people, have some caring responsibilities. This equates to more than 650,000 people in Scotland.

1.16 The “Voices of Carers” research (Scottish Government, 2005) suggests that carers are drawn from any social group, can be of any age, and can be male or female. About 1 in 4 carers were found to be in employment (with around 1 in 8 being in full-time employment).

1.17 The geographical distribution of carers is likely to be fairly even across Scotland. This has implications for policy and practice in that many carers live in rural areas and island areas. As will be set out later, geography is a key element in the delivery of short break services.

1.18 As will be set out in detail in the next section, when needs are assessed, the primary assessment is carried out on the cared-for person, although the needs of their carer should play a significant part in this assessment. In recent years, more and more local authorities have been providing structured assessments for carers, which take account of the needs of the cared-for person, but focus more directly on the impact of caring on the carer, for example, in terms of their mental and physical health. At present, however, the law does not permit the delivery of a social care service to carers as such, other than where a carer meets one or more of the eligibility criteria set out in the legislation for community care services *in their own right* (although one of the options explored in the recent Self Directed Support Bill consultation was an amendment to the 1968 Social Work Scotland Act to widen the definition of “person in need” to cover carers).

1.19 From a service delivery perspective, the actual recipient of the short break is, therefore, the cared-for person. At present, carers cannot receive a short break in their own right, although with the increasing use of flexible methods of delivery, the practical effect may be the same as if the carer was the recipient. The recent Scottish Government consultation on a Self Directed Support Bill raised the possibility that, in some circumstances, direct payments could be made to carers to take a short break, but it remains to be seen whether or not these proposals will be included in the Bill as presented to Parliament.

## ***The cared-for person<sup>5</sup>***

1.20 As set out above, there are two partners in a caring relationship. In recent years there has been a much stronger recognition of the rights of disabled people, older people and those with long term conditions to live independently. The definition of “independent living” agreed by a broad coalition of interested parties<sup>6</sup> is as follows:

*“Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.”*

1.21 In this context, independent living recognises the role of other family members and friends in supporting this right. It also recognises that disabled people and older people (as the “cared-for persons”) should be able to exercise free choices generally in partnership with family members who may participate in their support package, albeit on an unpaid basis.

1.22 In the context of short breaks, there is now a widespread recognition that, in the past, many disabled or older people were denied choice, or had to accept periods of “respite” in unsuitable accommodation. Examples were provided by interviewees of people in their 40s with multiple sclerosis having been placed in nursing homes where other residents were elderly. The avowed purpose of this was to provide “respite” for their unpaid carer. As will be set out in Section 3, this is changing, albeit slowly, with the advent of more flexible in-home short breaks and supported holiday options.

## **National policy context in relation to unpaid carers**

1.23 Since 1999, there has been a focus on unpaid carers, starting with the publication the first “Strategy for Carers in Scotland” (Scottish Executive, 1999). That led to a range of developments, including legislation and investments in support for carers.

1.24 In 2004, the then Scottish Executive commissioned the Care 21 report “The Future of Unpaid Care in Scotland”. This report involved a considerable volume of work, including a survey of 5,000 carers and a number of focus groups. Evidence from carers’ organisations which contributed to this research suggested that many of the findings of the Care 21 survey remain valid (as noted earlier), and, rather than carry out work which would replicate this, and which, in itself, would add little to knowledge about carers and the issues facing them, data from the Care 21 survey has been used in this report.

1.25 In 2008, the Scottish Government published fresh guidance on “Short Breaks (Respite)”, which set the issue in the wider context of national outcomes and national indicators, and made a wide variety of recommendations designed to assist “local

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<sup>5</sup> The term “cared-for person” is used for simplicity, as this covers people with a wide range of impairments and conditions. The term is used here alongside a clear underpinning recognition of the right to independent living.

<sup>6</sup> The Independent Living in Scotland Project, supported by the EHRC and Scottish Government.

*service planners improve short break provision*". The presumption of the Scottish Government was that this would lead to *"greater choice, flexibility and equity in the provision of short break services"*. The guidance set out a definition of short breaks (which is used for this research), and made a series of recommendations about the development of local strategies, engagement with carers and cared-for persons, and the delivery, monitoring and evaluation of services.

1.26 "Caring Together: The National Carers Strategy for Scotland 2010 – 2015" was launched in July 2010. This set out the strategic context for support to carers, and contained a specific chapter on short breaks. The purpose of the section was stated as being to:

*"... be clear about the importance of flexible, personalised short breaks provision, leading to better outcomes for carers and the people they care for."*

1.27 The Strategy described many of the benefits of short breaks and the challenges facing both carers and those seeking to provide short breaks. Perhaps the crux of the partnership-based direction proposed by the Strategy is contained in the view that:

*"all partners need to 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"*.

1.28 This research can perhaps make a contribution to these deliberations through its identification of both innovative solutions, and alternative approaches to the delivery of what may be regarded as "traditional" forms of short break.

1.29 Finally, the Strategy set out a number of actions specific to short breaks, and these are discussed in more detail in Section 5.

1.30 The focus on carers has been carried through in other policy areas as well. For example, the report of the 21<sup>st</sup> Century social work review "Changing Lives" made, as its first recommendation, that:

*"Social work services must be designed and delivered around the needs of people who use services, their carers and communities"*.

1.31 There has also been a strong focus on carers within the NHS, although, as will be set out in Section 2, the role of health services in relation to "social respite" is very limited. The Community Care and Health (Scotland) Act 2002 set out the basis of Carer Information Strategies, with a requirement that these be in place from May 2007. Much of the activity to support the implementation of Carer Information Strategies impacts, albeit indirectly, on short breaks, for example, through the continuing education programmes for GPs and front line health staff, which have a focus on identifying carers and on referring them to specialist services.

1.32 There has also been investment in organisations providing support for carers and cared-for persons. Much of this support is local, for example, through local

carers' centres or local disability / elderly forums, but there has also been support at a national level for a range of representative and service provision organisations.

1.33 As will be set out in more detail in Section 2, many areas have developed local "Carer Strategies", generally on a partnership basis between local authorities, the NHS and local carer organisations. In some cases, specific "Short Breaks strategies" have also been produced.

### **What is a short break?**

1.34 In 2008, the Scottish Government published specific guidance on short breaks. This identified the purpose of a short break as follows:

*"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 outwith an individual's home."*

1.35 The guidance goes on to define a short break as:

- Where there is no carer present, but the person with care needs requires a break from their normal situation;
- Breaks from caring where the carer needs a break; and
- Emergency crisis support where a carer needs an urgent break to prevent or respond to a crisis.

1.36 The term "respite" is often used interchangeably with "short break" in this context, but there is now a recognition that this is too limited, and does not accurately reflect the true nature of service delivery. Shared Care Scotland (SCS, 2010) summarised the distinction in the following way:

*"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' ... as we believe these are more acceptable descriptions. They imply the prospect of positive outcomes for everyone involved and shared benefits."*

1.37 Despite this, it was clear from this research that many local authorities still take a very traditional view of "respite".

1.38 As will be set out in more detail in Section 4, some local authorities, as well as carers' organisations, were considering ways of better defining the *outcomes* of short breaks. For carers, a primary outcome of a short break may be respite from caring. For a cared-for person, a primary outcome may be respite from "everyday" life or a normal routine. Accordingly, throughout this report, the term "short break" is taken to mean either a period away from caring responsibilities for a carer, or a period away

from a normal routine for a cared-for person. The term respite is used generally to describe an outcome for carers, to distinguish it from a short break.

1.39 The guidance is clear that a short break should, wherever possible, provide dual benefit, that is a benefit for the carer and the cared-for person.

### ***Types of short break***

1.40 There are a wide variety of potential types of “short break”. As will be set out later, as thinking has progressed on the role of short breaks (and the concept of respite within this), the range of types of activity regarded as a “short break” has increased.

1.41 Shared Care Scotland provides a glossary of short break types as follows:<sup>7</sup>

- Breaks in specialist respite accommodation .
- Breaks in residential care homes (with or without nursing care).
- Breaks in the home of another individual or family.
- Breaks provided at home through a care attendant or sitting service.
- Supported access to clubs, interest or activity groups.
- Holiday breaks.
- Befriending schemes where volunteers provide short breaks.
- Day care.
- Hospital-based respite.

### ***The legal position relating to carers and short breaks***

1.42 The law in relation to short breaks is complex, not least as there are two distinct parties involved, carers and cared for persons.<sup>8</sup> It is important to bear in mind that the recipient of the short break is always the cared for person, even though the carer may be the main beneficiary.

1.43 At present, carers’ rights are limited to, in all cases, having their views taken into account when an assessment is being carried out on a cared for person, and in cases where they provide a substantial amount of care, to requesting a carer’s assessment. Social work departments have an obligation, where they believe a carer provides a substantial amount of care, to inform the carer of this right.

1.44 Once a carer has received an assessment, it is important to bear in mind that this does not guarantee the delivery of any service directly to the carer. The only exception to this is where a carer is assessed as a person in need in their own right, and this may lead to a care package being provided. In the absence of this, a typical outcome may be a reassessment of the needs of the cared for person, perhaps leading to an increased level of service (which may include a short break). Carers may also be referred to a local carers organisation, which may be able to provide a wide range of support.

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<sup>7</sup> Full explanations of these terms are provided at Annex 1.

<sup>8</sup> Carers Scotland has published a useful guide “Carers and Their Rights”.

1.45 It is worth stressing that cared for persons are under no obligation to agree to a community care (or single shared) assessment, nor to accept any care offered, even where this may be of significant benefit to a carer.

1.46 At present, the terms respite and short break are not specifically defined in legislation, but fall under the general headings of a need for practical assistance or residential accommodation. It is important to stress that the recipient of this service is always the cared for person.

1.47 There are a range of other legal issues relevant to short breaks, particularly in relation to equality issues. Public bodies (including local authorities) have, for the last 3 years, had specific obligations in relation to disability equality, race equality and gender equality and these will soon be extended as a result of the Equality Act 2010. These provisions clearly apply to a large majority of cared for persons and carers, and require that public bodies must have due regard to (among other things) the need to promote equal opportunities and eliminate unlawful discrimination. Arising from this, public bodies must both proactively engage with groups covered by the legislation, and undertake equality impact assessments of both policies and services (taking any steps practical to remove or ameliorate negative impacts).

### ***The role of short breaks in a caring context***

1.48 The Care 21 report was a large and complex piece of work, involving both primary and secondary research and a large number of consultations with both carers and carers' organisations. Much of the evidence below is drawn from the Care 21 report.

1.49 The impact of caring on a carer can be considerable. Data from the Care 21 survey suggests that more than 60% reported feeling:

- Tired.
- Stressed.
- Lacking sleep.
- Anxious.
- Irritable.
- Depressed.

1.50 The survey suggested that the likelihood of these impacts rises with the intensity of caring, which includes not only the number of hours spent caring, but also the nature of caring tasks and the period over which care is provided. In essence, those who provide the most care are the most likely to suffer physical and mental health-related impacts. Almost half of all carers surveyed had visited a GP in the preceding year as a result of the health-related impacts of being a carer.

1.51 It is clear that caring has a significant impact on social and economic well-being. Nearly 90% of those surveyed felt that caring had had some level of impact on their social lives. For example, nearly 4 in 5 felt that it inhibited their free time, and around two thirds that it had been detrimental to other aspects of family life. Nearly half of all carers reported feeling lonely or isolated. As with health issues, there was seen to be a direct link between the intensity of caring, and the level of its social impact.

1.52 Evidence from Carers Scotland extracted from a UK-wide survey suggests that many carers face financial difficulties (which are beyond the scope of this research) but, related to this, many face social isolation which is exacerbated by a lack of access to short breaks.

1.53 There is clear evidence that short breaks can be effective in helping to address or ameliorate these issues. The recent Scottish Government guidance summarised evidence from a range of sources (including Care 21) in suggesting that short breaks are effective in:

- Helping carers to safeguard their health, avoiding physical or emotional exhaustion, and enabling adult carers to continue caring. In the case of young carers, the overall aim is rather to prevent inappropriate levels of caring, but 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, to develop independence and prepare for the time when the carer cannot continue caring.

1.54 This is only a partial list, and wider potential impacts may include:

- Preventing family breakdown, with the psychological, social and economic costs which accompany this.
- Preventing some emergency admissions to hospital.
- Helping to address the issue of bed blocking, and delayed discharge from hospital.
- Preventing, or at least delaying, admission to long term care.

### ***Self directed support and direct payments***

1.55 Since 1996, anyone assessed as having a requirement for a community care service has had the option of managing this care themselves, generally through a direct payment. In essence, this means that where an assessment includes a short break the nominal value of this can be included within an overall package of care. Two recent studies on Self Directed Support for the Scottish Government (Homer and Gilder, 2008; RHA, 2010) found increasing evidence that some families were using direct payments as a way of exercising greater choice in relation to short breaks, and, in some cases, as a way of circumventing a lack of options within local authority delivery. The findings of this research in relation to Self Directed Support and direct payments are set out in Section 3.

### **Evidence about the extent of short breaks**

1.56 Evidence on the extent of short breaks comes from two main sources: the Care 21 survey and the annual returns provided by local authorities to Audit Scotland

and the Scottish Government. These datasets are not comparable and have been reported separately below.

### **Evidence from Care 21**

1.57 The survey carried out as part of Care 21 suggested that about 61% of those surveyed had had a break from caring spanning more than 2 days. Of those that had not, about 36% felt that they had not needed a break. However, it is worth noting that a similar percentage (equating to 14% overall of the carers surveyed) were unaware that they could access a break, or were unaware of how to go about this. Younger people aged up to 44 were least likely to be aware of this.

1.58 Among those that had had access to a short break, the following table sets out the nature of the provision used.

**Table 1. Forms of short break provision used**

<b>Nature of provision</b>	<b>Percentage used</b>
Nursing or residential home	21
Friend or relative staying with person cared for	17
Stay with relatives or friends	12
Arranged holiday	6
NHS hospital	4
Support from external / paid carers	3
Local authority hostel	2
Stay with a volunteer family	1
Person left on own	*
Breaks while at a day centre	*
School trip	*

1.59 Around 4% of those surveyed suggested that they had been offered a break, but had considered this to be unsuitable. The main reason given for this was that the cared-for person would be unhappy, or was unwilling to accept the option offered but others mentioned a lack of suitability for their needs, as well as a wish for a family holiday, rather than the form of break offered.

1.60 A clear finding from the survey was that views of the “best” type of short break were very varied, and were generally a matter of the personal choices of the carer and cared-for person. Some respondents preferred breaks of a few hours, others of a few days and, in some cases, particularly where the preferred option was a care home, longer. Some preferred a break with the cared-for person, others without him or her. Some wanted a break in their own home, others in an external location. The research also suggested that many carers expressed a view in favour of more than one type of care, for example, favouring both a family holiday and a sitter service, depending on the circumstances. There were also variations expressed in the desired level of frequency of breaks.



1.61 As might be expected, there were clear differences in the preferences of carers depending on the intensity of the care they provided. In essence, those with the most intensive caring responsibilities were most likely to opt for residential care as their preferred option.

### ***Evidence from local authority returns***

1.62 The Scottish Government has published respite statistics for two years. Previously, some statistics had been available in the form of comparative performance tables from Audit Scotland. As with any dataset, there have been early teething problems relating to consistency of definitions and the consistency of counting (and consistency across years), but these statistics do provide a good overview of the volume of short breaks provided across Scotland.

1.63 In 2009-10, a total of 203,360 weeks of short breaks were provided to all ages (including those aged 0 – 17 which are outside the scope of this research). A total of 73,800 weeks were delivered to adults aged 18-64 and 105,690 week to older people aged 65 and over.

1.64 A clear majority (123,580 weeks or 68.9%) took the form of day short breaks, while the balance was of overnight short breaks. The pattern of short breaks has been changing over time, with day short breaks increasing and overnight short breaks declining (although neither change is particularly large).

1.65 Although there are issues with the accuracy of the data at individual local authority area level, there is evidence of significant differences in the overall level of provision of both day and overnight short breaks across areas. These are discussed in more detail in Section 4.

### ***Limitations of these analyses***

1.66 From this research, it was clear that local authorities have been struggling to properly account for the short breaks they provide directly, or fund through Self Directed Support using traditional volume-based measures such as “nights” or “weeks”. A number of local authorities were identified as considering how best to develop performance measures based on the outcomes achieved, rather than volume, and this will be described in more detail in Section 4. A recommendation in relation to supporting and developing this work will also be made in Section 5.

### **The next section**

1.67 The purpose of this section has been to provide an overview of the nature, context and overall level of short breaks provision in Scotland, to provide the background to the findings which will be described in the remainder of the report. The next section will deal with the local policy context, including local partnerships and the development of strategies and action plans.

## **SECTION 2: THE LOCAL POLICY CONTEXT**

2.1 This section will set out information about the local policy context within which short breaks fit. It is important to recognise that short breaks do not exist in a vacuum. A short break is likely to be only one component of a care package put in place by a local authority to support a cared-for person and their carer. The process for identifying needs, both of cared-for persons and carers, will be set out in more detail in Section 3, however, the components of a care package are likely to include at least one and usually more of the following forms of support:

- Attendance at a day service.
- Attendance at a specialised unit.
- Home care for domestic and basic personal care.
- In-home nursing care.
- In-home support by a Personal Assistant or agency staff member.

2.2 Increasingly, social care is also being delivered through the application of technology, and many local authorities have implemented forms of “telecare”, which either replaces or supplements any of the services set out above. Telecare, as with other forms of provision, will be described in more detail in Section 3.

### **Strategic approaches**

2.3 It was clear from this research that there was no single strategic approach taken at a local level. It would be fair to suggest that there were effectively 32 variants.

### **Structures**

2.4 Before considering the strategic context for short breaks, it is worth noting that there was no standard structure either for the planning or the delivery of care, and within this, short breaks.

2.5 At a macro level, all social care is planned and delivered through community planning partnerships. A number of local authorities referred to joint community care plans as delivering overall direction on social care, although it was recognised that there was likely to be little (if any) detailed coverage of short breaks within joint community care plans.

2.6 In all areas, as will be set out later, there was joint working between social care, health and the voluntary sector (at least), which generally involved joint planning and oversight of care and carer issues, even where the delivery of services was entirely through one partner.

2.7 A number of areas had effectively integrated social care and health services, or were in the process of doing so. Within this, however, it was clear that there were variations in the extent to which the planning and delivery of individual services was integrated. In one area, for example, while overall strategic planning was integrated, the planning and delivery of short breaks was identified as being entirely undertaken by former social work service staff.

2.8 Even within areas where social care and health services remained separate, there was evidence of a variety of structures. For example, virtually all social work departments were functionally split into client group service delivery areas, generally, children and young people, adults and older people. Most also identified specific teams dealing with individual client groups (e.g. disabled people, people experiencing mental health problems, people with learning difficulties etc.), but the pattern of these varied widely across Scotland.

2.9 It was identified that, in some rural and island areas, structures may be simplified, with areas of responsibility being combined.

### ***Roles and responsibilities***

2.10 There was a clear view that responsibility for short breaks rested primarily with social work services, although delivery of the short break may be contracted to a voluntary or private sector provider.

2.11 In a handful of areas, carers' organisations had been provided with delegated funding to provide short breaks, most commonly in conjunction with other activities promoted by the organisation such as training. However, this represented a tiny fraction of the overall volume of short breaks delivered in Scotland.

### ***Nature of strategies and plans***

2.12 At a broad strategic level, carers issues were found to be included in a wide variety of over-arching strategies and plans, even though short breaks may not be mentioned, or covered in any detail. Examples of these higher level strategies which may cover carers' issues were found to include:

- Single Outcome Agreements.
- Community Plans.
- Joint Community Care Plans.
- Joint Health Improvement Plans.

2.13 Carers' issues may also be covered in the strategic or delivery plans of local authority service departments, NHS Boards or Community Health Partnerships (CHPs).

2.14 Scottish Government guidance suggests that:

*"It is for local partnerships to decide whether to develop specific Short Break Strategies or to include their strategic planning in wider Carers' Strategies, Community Care Plans, Integrated Children's Services Plans or plans for specific groups of service users. However, where local short break planning is split between different strategic plans, it would be good practice to pull out the short break elements into a single document ..."*

2.15 There were three main approaches identified in this research in relation to the strategic context within which the planning and delivery of short breaks fitted. These could be characterised in the following ways:

- A dedicated short breaks strategy.
- A carers' strategy which also covered short breaks.
- Strategies for specific client groups which also covered short breaks.

2.16 These approaches were not mutually exclusive as, for example, some interviewees referred to short breaks being identified both within carers' strategies and within client-group specific strategies. One local authority referred to short breaks as being covered in "6 or 7 separate strategies".

2.17 It is important, however, to draw a distinction between having a clear strategic direction and a written strategy. Even where there was no written strategy, it was not suggested that this meant an overall lack of strategic direction.

#### *Dedicated short breaks strategies*

2.18 A small minority of areas had developed dedicated short break strategies (however described). It would also be fair to suggest that there was little evidence that many other local authorities or partnerships intended to take this approach. Among the reasons given for this were:

- No identified need as issues were covered by other strategies.
- A view that, as the services were delivered on a service group basis, this would also be the best level at which to provide direction.
- A concern about "yet another strategy", potentially leading to confusion and duplication.
- A view that short breaks were a "small part" of community care overall, and that it would be "nonsensical" to "tease out" one part.

2.19 One local authority indicated that it was waiting for the National Carers Strategy to be published before reaching a final decision on whether or not to have a short breaks strategy.

2.20 In all cases where short breaks strategies were identified, these had been developed on a multi-agency basis, generally involving carers' organisations and the NHS, and, in some cases, care providers in the voluntary or private sectors.

2.21 As might be expected, these strategies were viewed as multi-agency, even where some of the agencies (particularly the NHS) did not have a direct role in delivery. In one case, it was indicated that the short break strategy did not include the NHS although it did cover both voluntary and private sector service providers.

#### *Carers' strategies*

2.22 A large majority of areas identified that they had developed carers' strategies of some kind, although evidence suggests that a number of these were out of date or otherwise requiring revision<sup>9</sup>. A number of local authorities indicated that their carers'

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<sup>9</sup> It is not possible to be definitive about how many, as some interviewees were unaware of the status of their Carers Strategy, and it was not always possible to identify whether strategies available through, for example, local authority or national voluntary organisations' websites were the most up to date.

strategies would be updated once the National Carers Strategy became available.<sup>10</sup> One local authority suggested that, although its carers strategy was “some years old”, it was “still relevant”. Another noted that its carers strategy was “pre-2004”. In one area, the local authority concerned identified both a carers and a young carers strategy.

2.23 Carers’ strategies were, in all cases, seen as multi-agency, covering both the statutory and voluntary sectors.

#### *Specific service or client group strategies*

2.24 All of the local authorities which took part in this research indicated that some form of strategies existed either for individual services or individual client groups.

2.25 As noted earlier, there was evidence of a variety of individual structures within social work services. In some areas, strategies appeared to be developed at the level of broad groups of service users, while in others, a further layer was identified, generally focusing on smaller sub-groups of clients.

2.26 Two local authorities indicated that short breaks were dealt with within the overall context of individual service improvement plans, for example, covering older people, dementia, mental health or learning difficulties. These plans were identified as relating only to social work services.

2.27 It was clear that, in some areas<sup>11</sup>, written strategies existed for some groups but not others. For example, one local authority identified both an older people’s strategy and a strategy for learning difficulties, but none covering physical or sensory impairments.

2.28 It was beyond the scope of this research to examine individual client group strategies, but, from comments made by interviewees, the level and depth of coverage of short break issues was likely to vary widely. One local authority, which noted having a number of client-group specific strategies or policies, suggested that all but one of these contained “very very little” about short breaks.

2.29 Generally, it appeared that client-group specific strategies were multi-agency, whereas service plans related only to social work services.

#### ***NHS Carer Information Strategies***

2.30 All NHS Boards have Carer Information Strategies. Even though none of the NHS boards or local authorities which took part in this research identified a direct role for health bodies in the way short breaks are currently delivered, the *delivery* of these strategies has some indirect impact on short breaks, for example, through work with GPs to identify people with caring responsibilities and referrals to carers’ organisations.

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<sup>10</sup> It was published in July 2010 after the fieldwork for this research was completed.

<sup>11</sup> It is impossible to be definitive about how many areas as interviewees were not always fully aware of the status of service-group specific plans.

## **Overall direction and the locus of responsibility for short breaks policy**

2.31 As set out earlier, there was a virtual consensus that overall responsibility for the delivery of short breaks currently rests with local authorities. The locus of overall responsibility for the direction of policy on short breaks was more complex.

2.32 Within local authorities, overall responsibility was found generally to rest with a Head of Community Care or similar post, but, below this, there was evidence of a variety of approaches. In some cases, a single service manager had responsibility, but more generally this was shared among heads of service. Even within this latter model, there was evidence of variations with, for example, one service manager providing a co-ordination function in relation to the compilation of data and the submission of reports to committees or the Scottish Government; or in leading in engagement with carers and carers' organisations.

2.33 A number of interviewees made the specific point that, given the structures in place, it would be difficult for a single manager to be responsible for all aspects of short breaks. As will be set out in more detail in Section 3, there were also found to be a wide range of individual social work (and similar) teams involved in the delivery of aspects of short breaks.

2.34 In some cases, it was clear that strategic or joint working groups had a role, generally in advising on the direction to take. In several areas, for example, a Carers Strategy Group, however described, was noted as having a role.

## **Engagement with the voluntary sector and with carers**

2.35 It was clear from the research that a large majority of local authorities have a high level of engagement with the voluntary sector and with carers as well as with organisations of and for various client groups. The research identified a wide variety of structures, all of which involved carers' organisations and local authorities, as well as NHS Boards and, in some cases, CHPs.

2.36 The research identified a substantial number of ways in which local authorities, or local partnerships, engaged with carers, carers' organisations, service users and service users' organisations. As stated above, there were found to be a range of strategic partnerships, some specific to caring, others focused on issues facing specific client groups. Most interviewees indicated that, where strategic groups existed, these virtually always included representation from at least one carers' organisation, and, in some cases, individual carers. Clearly, in these cases, there would also be representation from cared-for persons.

2.37 It was clear that, in all areas, a formal structure exists through which local authorities seek to engage with carers. In some cases, this was through a carers' centre which delivers services under contract to a local authority, while in others it may be through one or more carers' organisations which obtain funding from other sources.

2.38 There were many positive views expressed by local authority and NHS interviewees about both the roles of carers' organisations and the part they play in

both strategic and operational matters. It was also clear that a parallel role may be played by, for example, local disability forums, or older people's groups.

2.39 The nature of both carers' and service users' organisations were identified as varying across Scotland, although the roles played were, in effect, very similar. There were a number of examples provided of co-operation between local authorities (or partnership) and both carers and service users organisations. One examples was related to the development of options, an option appraisal and a wider consultation on facilities for adults with learning difficulties. A small number of interviewees also mentioned direct involvement by a Community Care Forum (or similar, such as a Council for Voluntary Service), either as a direct partner in strategic and operational work, or in supporting the voluntary organisations involved in these processes.

### ***The development of strategies***

2.40 In all cases where either dedicated short break or carer strategies were found, these were developed either by a multi-agency group involving the voluntary sector and carers, or at least through joint working with them. A number of means of bringing this about were identified including:

- Direct consultation with carers through events, questionnaires and direct contact.
- The use of feedback from carers and service users obtained through a variety of means (see Section 4 for more details of this).

2.41 In one case (a short break strategy) it was suggested that the "writing team" had involved representatives of both carers' organisations and public bodies.

2.42 A summary of an example of a process of consultation is set out below:

*"... consultation has taken place in various formats with a range of people including providers of short breaks, from users of short breaks and a variety of carer support groups from all client groups to establish what people's experiences have been both positive and negative. The consultation also sought to establish areas for improvement / development for increased flexibility to enable future service delivery to be more personalised. Feedback has also been received from practitioners who have described the complexities and difficulties identifying suitable breaks for service users and their carers / family members ..."* [Midlothian Council Short Break Strategy]

2.43 Although this research found that much of the engagement with carers appears to have been focused on strategy development either in relation to short breaks or more widely, on carers' strategies, it was evident that there were other ways in which the statutory and voluntary sectors were working in partnership seek to engage with carers. In some cases, these engagements were part of a regular pattern while, in other cases, these were one-off processes or events<sup>12</sup>.

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<sup>12</sup> It is worth noting that carers' organisations maintained a regular dialogue with carers (and often cared-for people) about short break issues, regardless of whether these were related to a specific exercise.

2.44 Among the ways used to engage with carers identified by the research were:

- Consultation events.
- Open days.
- Open forums (which may be themed in some cases).
- Carers' conferences.
- Newsletters.
- Questionnaires.
- Interactive video booths.
- Leaflets.
- Surveys (telephone and letter).

2.45 Examples of carer and service users' involvement in pilot projects were also provided, including both single shared assessment and carers' assessment pilots.

2.46 A small number of local authorities (less than a quarter<sup>13</sup>) identified carrying out carers' surveys. Some lead officers identified undertaking a regular structured programme of liaison visits with organisations.

2.47 One example of an ongoing dialogue with carers was given by a local authority and carers' centre which promote regular carers conferences, including one focused on strategic planning issues. It was noted that this was regarded by the local authority as part of its planning cycle, and was timed to be able to influence choices and decision making. It was suggested that the success of these area-wide conferences was likely to lead to the development of smaller local events in future. In addition, it was noted that on two occasions each year, a session was jointly facilitated between carers and local authority staff to discuss issues arising in relation to care, including short breaks. These were described by the council as being "very helpful".

### ***Engagement with voluntary and private sector providers of services***

2.48 This was identified by some interviewees as a complex issue as carers' organisations, as well as older people's and disabled people's organisations may provide some short break services either under contract to a local authority, or using funding specifically provided for this purpose. A good example of this was where carers' centres had been provided with a specific budget by their local authority to provide short breaks in certain, generally well-defined circumstances. There was no suggestion that the acceptance of this role had required the withdrawal of these organisations from a representational role.

2.49 The position of other service providers was less clear, where, for example, a decision had been taken not to engage with private sector providers of residential care services in the development of strategy or policy. One local authority, for example, indicated that this had been done as a way of ensuring transparency and impartiality. However, it was also clear that, in other areas, providers had been included in the strategy and policy development process.

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<sup>13</sup> Again, it is difficult to be definitive as some interviewees may have been unaware of, for example, small scale surveys undertaken on a client-group specific basis.



2.50 Regardless of whether or not providers may have been involved, as will be set out in Section 4, local authorities all had detailed procedures in place for gathering information, and, in most cases, feedback, from providers.

2.51 In May 2010, Shared Care Scotland convened the first of what was expected to be a series of workshops aimed specifically at providers. It was intended that the agendas would be set by providers, and that these should focus on areas of common interest. The first meeting attracted more than 40 providers, with considerably more registering an on-going interest.

### **Joint working on specific issues**

2.52 There were a large number of examples of joint working for specific issues identified, both at a local level, and increasingly, at a national level. Much of the work identified earlier in relation to the development of strategy and policy has been undertaken jointly by social work, health and the voluntary sector, but a variety of other work was also identified, some within disciplines, some multidisciplinary.

2.53 Examples of this included a number of Scottish Government working groups, including those involved in the development of both the National Guidance and National Strategy. A number of examples were also provided of joint working on specific issues, some facilitated by the Scottish Government, some by CoSLA and some by national voluntary organisations.

2.54 Shared Care Scotland has supported a number of action learning sets, bringing together practitioners on a multi-disciplinary basis to investigate topics of common interest. Two of these which will be referred to later in this report were the sets dealing with Short Breaks Bureaux and the development of a common evaluation framework.

2.55 There were also a number of examples provided of individual local authorities working together to address specific issues. The issue identified most often was Short Breaks Bureaux, but joint working on assessments was also noted. In one case, it was suggested that work on improving assessment processes was being led by the voluntary sector.

### **Views about the purpose of short breaks**

2.56 The research identified a high level of agreement about the purpose of short breaks within the context of the relationship between the carer and cared-for person albeit that these were described in a variety of ways.

2.57 The bullet points below summarise some of the key purposes of short breaks expressed in interviews. The first group relate to cared-for persons and included:

- To reduce interventions and to enable cared-for persons to be more independent.
- To help promote re-enablement.
- To allow the cared-for person to participate in social activities while providing respite for their carer particularly, but not exclusively relating to day centre provision.

- To delay or prevent admission to long term care.
- To prevent delayed discharge from health care settings.
- To provide a break from “everyday life”.

2.58 There were also a number of purposes identified for carers, including:

- To help carers to continue to provide care, described in various ways including, for example, “keeping carer’s afloat” or “preventing carer breakdown”.
- To allow carers to participate (at all or more fully) in everyday activities.
- To help reduce the isolation faced by some carers.
- To provide a better quality of life.
- To provide a break from “everyday life”.
- To help maintain carers’ health.

2.59 Some of these purposes were shared, in the sense that they applied to both cared-for persons and their carers. The most commonly mentioned among these was the maintenance, or enhancement of the relationship between the two parties. This was described by one interviewee as *“helping the stability of the family”*. Another noted that:

*“many families are in an overall state of crisis and respite has a role in helping them cope”.*

2.60 These purposes were consistent with those set out in the National Guidance and identified in Section 1. There was also a focus on the potential outcomes of short breaks. These are summarised in more detail in Section 4.

2.61 There were found to be some variations in view among local authorities as to what should be considered to be a short break (or “respite”). The most common variation related to day care. A small number of interviewees suggested that day care should not be regarded as “respite”. Others, however, suggested that, (following guidance from Audit Scotland, where attendance at a day care facility was provided as part of a care plan, or following a carer’s assessment, it may be considered as this.

2.62 One local authority also noted that, as a matter of policy, “short breaks” would not be provided in cases where no carer would benefit. However, it was acknowledged that other ways had been identified of providing a similar benefit to people with no carer as would be available to someone with a carer, for example, through using client-group specific budgets.

2.63 A small number of interviewees suggested that short breaks were not designed to help enable carers to go to work, or to attend college or training, although some carers’ centres reported having specific budgets to provide care to enable carers to attend training courses related to their caring role.

## Measuring demand and unmet need

2.64 For the most part, local authorities identified that the main means for measuring demand for short breaks was through assessments carried out with service users. In essence, aggregate demand would be the sum of individual assessments. Most, however, supplemented this by other measures. These were found to include:

- Regular conversations with carers and service users' organisations both on a free-standing basis and as part of strategic groups.
- Monitoring patterns of service provision.
- Feedback from individual carers and service users.
- Benchmarking with other areas.

### ***Unmet need***<sup>14</sup>

2.65 There was a virtual consensus that measuring *unmet* need was very difficult, with some viewing this as effectively impossible. Interestingly, very few interviewees believed that there were no areas of unmet need in their area. In some cases, aspects of the work to measure expressed demand (e.g. statistical analysis and benchmarking) were highlighted as ways of identifying areas of unmet need as well, as were conversations with carers and organisations. NHS respondents identified work done by front line staff to identify hidden carers as being valuable in this regard.

2.66 A small number of examples were also identified of specific survey work with individual client groups, but there were mixed views of the effectiveness of this. In one area, a carers organisation had been commissioned to facilitate focus groups across the local authority area. In other areas, both local authorities and carers' organisations had facilitated open forums or other forms of consultative event. It was also noted that carers' organisations in some areas would maintain data on levels of unmet need as expressed by members and clients.

2.67 A number of interviewees identified a range of ways in which partner organisations sought to identify carers and promote the benefits firstly of accessing a carers organisation and then, potentially, short breaks and other forms of support. In addition to work done by the NHS as part of the implementation of Carers' Information Strategies (mentioned earlier), examples included:

- Events and publicity around carers week.
- Free-standing events.
- Newsletters.
- Presentations to groups likely to contain hidden carers.
- Seeking newspaper / radio coverage.

2.68 In addition, it was noted that local authorities and carers' organisations also worked with other professionals to try to raise awareness of the need to identify and provide basic assistance to hidden carers. Examples given included Citizens Advice

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<sup>14</sup> For the purposes of this report, a distinction will be drawn between unmet need and unmet demand, where the latter is restricted to cases where a need is identified, for example, through an assessment, but cannot be met.

Bureau and Money Advice staff, and staff at day centres. A number also cited education staff in relation to young carers.

2.69 There was a clear view that the identification of latent, or unmet need was seen as valuable. One interviewee noted that:

*“it is valuable for both current and future planning. It’s an early warning, and an indication of where something needs adjusted”.*

2.70 One local authority indicated that work to identify unmet need had led to a specific initiative with service users with pre-senile dementia. Another noted their work with service users with mental health problems in the same context.

2.71 At a wider level, it was also noted that views of unmet needs would also feed through into strategy development although in some cases, the resulting service provided may not include short breaks per se. One example was provided of steps being taken to better promote day centres and lunch clubs, as well as informal social opportunities. However, it is also worth noting that some local authorities were less positive about the impact of the identification of unmet need, suggesting, for example, that this was circumscribed by a lack of data, or a lack of specific evidence on which action could be based.

2.72 A small number of interviewees suggested that simply measuring expressed or assessed demand or identifying hidden carers was not fully adequate. One noted, for example, that these processes would be likely to identify only demand for traditional forms of short breaks, and that work had to be undertaken in tandem to explain wider options. One tied this to the philosophy of outcome-based assessments and personalisation.

2.73 Overall, there was a general view that the partners involved were “not very good” at assessing levels of unmet need. One interviewee noted: *“we’re not very good at seeing what’s not there”*. It is worth noting that some interviewees suggested that this could be an area in which the Scottish Government or Shared Care Scotland could assist in the development of good practice guidance.

### **The next section**

2.74 Having outlined the findings of the research in relation to the local policy context, the next section of the report will focus on delivery issues.

## **SECTION 3: DELIVERY ISSUES**

3.1 The research also explored delivery issues and these findings are presented in this section.

### **Local approaches to the delivery of short breaks**

3.2 The delivery of short breaks was found to vary from area to area, with a number of different types of structure in place.

#### ***The process***

3.3 It was found that the first stage of the process would, in virtually all cases, be an assessment of the care needs of an individual, and generally of their carer or carers<sup>15</sup>. The content of assessments will be discussed in more detail later (and was found to vary across local authorities) but, in nearly all cases, these would be carried out by social work staff. In one area, where the health and social care teams had been integrated, nurses were identified as undertaking some assessments. It was also noted that social work assistants, or social work students on placement may also carry out some assessments, although these would be checked subsequently by qualified staff. In most areas, cases would be allocated to area-based teams, although in one area, it was noted that a centralised team dealt with all new referrals, including carers' assessments.

3.4 While this first stage of the process was found to be broadly standardised, the next stages were found to vary between areas. The following comments assume that, following a single shared assessment or carers' assessment, a period of respite or a short break has been identified.

3.5 In a large majority of areas, the identification of the break and its planning would be undertaken in conjunction with the client and their carer by the social worker who completed the assessment. The main area of variation was found to be in whether or not that social worker would have access to a specialist resource, generally either a Short Breaks Bureau or a dedicated short breaks worker. The work of Short Breaks Bureaux will be described in more detail later.

3.6 A number of issues were raised with this aspect of the process both by local authority and other interviewees. The main concern was that the success of the process rests heavily on the level of knowledge of individual social workers. It was suggested that they may not always be aware of some options which may be beneficial to the cared-for person and carer. It was also suggested that there may be an over-reliance by social workers on traditional forms of short breaks, particularly breaks taken in care homes.

3.7 All local authorities identified that approval processes were in place designed to ensure both that service users were eligible and that best value was being achieved. The level of formality of these was found to vary. In relation to the level of

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<sup>15</sup> The only real exception would be where an emergency need arose and where the client had had little or no previous contact with social work services. In these cases, a short break may be arranged without recourse to a full assessment (although this is likely to be done soon afterwards).

approval, in most cases, it appeared that routine decisions were delegated to individual care managers, while in a small number of cases, approvals were provided through a centralised panel-based system. In relation to the latter, there appeared to be some variation in whether or not, once a care plan was approved, individual strands of it, including short breaks, would also require separate approval.

3.8 Most local authorities identified specific limits to the number of breaks which could be taken. In some cases, this was expressed in terms of numbers of nights or weeks, or, less usually, in terms of overall cost. A clear majority of interviewees identified a limit of 6 or 8 weeks, although some suggested 10 or 12 weeks. In a small minority of cases, local authorities indicated that there were no formal limits, but that cases would be assessed on merit.

3.9 One interviewee suggested that limits based on weeks (or nights) may be inappropriate when service provision was being seen to move away from overnight-based and generally traditional forms of short breaks. It was also suggested that such limits would be difficult to translate to cases either where most short breaks were provided in-home by an agency, or where an out-of-home short break would be particularly expensive as a result of a requirement for additional support, for example, where a service user exhibited challenging behaviour, or required significant levels of nursing care.

3.10 It was also acknowledged that, in some cases proposals could be too expensive, even where very flexible short breaks were offered. Again, it was suggested that these would be considered on a case by case basis. Among the options identified by interviewees in these cases were:

- Amending the proposed break to reduce the cost.
- Securing a contribution from the service user or carer.
- Securing a contribution from a charitable source.

3.11 In a small number of areas, it was also suggested that an alternative approach could be to reduce the overall number of nights of short breaks taken, in effect allowing for a higher per night cost, while requiring the same overall budget. This approach, in the context of more flexible planning of breaks, is discussed in more detail later.

## **Charging**

3.12 Although charging was not covered directly in this research, it was noted by a number of contributors that there were variations in charging policy between local authorities, and that the level of charges themselves may serve as a disincentive to some people to seek social care services generally, and short breaks specifically.

## **Personalisation**

3.13 The research identified that one of the key drivers in the local delivery of short breaks was personalisation. In “Changing Lives – The 21st Century Social Work Review”, personalisation was described in the following terms:

*“Increasing personalisation of services is both an unavoidable and desirable direction of travel. Unavoidable in the sense that both the population and policy expect it; desirable in the extent to which it builds upon the capacity of individuals and communities to find their own solutions and to self care, rather than creating dependence on services.”*

3.14 It was clear that there was a strong focus on personalisation in virtually all local authority areas. This was manifest in a wide variety of ways and was integral to a number of carers’ strategies, short break strategies and client group-specific strategies. One example of this is set out below:

*“Many carers want some form of respite that involves the person they care for being cared for outwith their home. But many also want a break away together with the person they care for, as they worry about their loved one being unhappy at being apart, or that some of their needs might not be met, e.g. food preferences or cultural needs. Some carers would prefer more flexible respite, for example at day care, or a sitter to let them out for a while, especially in the evenings or at weekends.” [Dundee Carers’ Strategy, 2008-2011]*

3.15 The pace of change was evident, however, was variable, not only between local authorities but also across client groups. For example, one local authority indicated that it intended to introduce a new approach for older people first while, in another case, adults with learning difficulties were to be the subject of changes. Overall, however, it would be fair to say that most local authorities indicated that they were making progress towards a more personalised approach.

3.16 In only one case did a local authority indicate that it was facing significant difficulties which might preclude progress on personalisation. It was suggested that:

*“being client-focussed is our basic overall objective, but it is very hard to do when resources are limited. Some things are squeezed, some get a lower priority. You have to make hard choices, which are not always popular”.*

3.17 Before describing aspects of personalisation, it is worth noting that a significant minority of interviewees suggested that moves towards personalisation, and towards more tailored services generally, may be made more difficult by what was described as “traditional” thinking, largely (in their view) on the part of clients, but also, in some cases, staff. This was most obvious in the fact that a significant number of older people were reported to prefer short breaks in a care home setting. One interviewee suggested that this was not incompatible with personalisation, provided that options were offered, the choice was freely expressed, and the quality and nature of the provision appropriate. As one interviewee noted:

*“The simple fact is that many older people just prefer a care home. Their carers also have a lot of trust in this model. The issue is about working with this, not against it”.*

3.18 A number of elements of personalisation will be discussed in more detail below, however it is worth summarising these here. Although seen differently and expressed differently, personalisation was seen to encompass, for example: assessments and moves to a more outcome focussed approach: Self Directed Support; Short Breaks Bureaux; and a move away from block booking provision. As will be set out later, a range of other issues, such as telecare, also impact on moves towards increasing personalisation.

## **Prevention**

3.19 A key theme of much of the work being undertaken by local authorities was found to be the prevention of both carer “breakdown” and either delaying or preventing admission to long term care. As was set out earlier, in most cases, these were seen as primary purposes of short breaks and mechanisms for making services as effective as possible were identified both directly and indirectly. One local authority noted that:

*“this is really the key to our overall provision”.*

3.20 Central to the approach of some local authorities was “re-ablement”, or as expressed in some cases, supported independent living. The basis of the approach identified involved a co-ordinated response both to people about to be, or recently discharged from hospital and those struggling in their own homes. The approach involved advice, assistance, targeted services and often technology to help support service users, and by extension their informal carers, usually over a relatively short, defined period. Re-ablement would generally be a free-standing service, and would be unlikely to include short breaks, at least directly. However, it was clear that a period of re-ablement may be a precursor to a longer term package of care being developed which would be likely to include short breaks.

3.21 Telecare is described in more detail elsewhere, but it is worth noting here that a significant minority of local authorities identified this as critical in supporting people to remain in their own homes for as long as possible. It was also suggested that the presence of telecare could help prevent carer breakdown, as it allowed the carer more freedom to engage in out-of-home activities.

3.22 It was also clear that local authorities also viewed improvements in assessments and monitoring as important factors in relation to prevention, as it was identified that a period of “emergency” care may be the trigger for a move to long term care. Hence, it was suggested, a focus on better planning and the avoidance of crisis could have a significant role to play in prevention.

3.23 A number of other types of short break as well as some mainstream services, particularly home care, were also identified by interviewees as contributing to prevention. For example, it was suggested that access to day care could fulfil this role, partly in terms of its impact on the carer, but also in terms of the positive and beneficial impact on the cared for person in terms of, for example, reducing isolation.



## **Assessments**

3.24 As noted earlier, access to community care services is triggered by an assessment carried out of the needs of a service user. It was clear from this research that a significant number of local authorities had undertaken work to redesign or re-orient the assessment process to make it more effective. In all cases, this was allied to developments in the assessment of carers' needs.

3.25 The main change in assessments was generally described as being to introduce (or reinforce) a focus on identifying and meeting outcomes for service users and their carers. It was clear that some local authorities had made more progress than others on this, and it is worth noting (as will be set out later) that the need for additional work on identifying and measuring outcomes was identified as being required at a national level.

3.26 A small number of local authorities indicated that changes had been made to assessment pro-forma to make these both simpler and easier for both clients and staff to understand.

### ***Talking Points and similar approaches***

3.27 Although a small number local authorities indicated that they were developing a bespoke methodology for assessments, the most common approach mentioned was the use of "Talking Points". The essence of the Talking Points methodology is to promote an holistic approach to assessment and review by care managers regardless of their discipline.

3.28 The template used appeared to vary from area to area, but was likely to include domestic and personal care, mobility and dexterity, socialisation and relationships. The resultant assessment would, with the client's permission, trigger the development of a care plan which would be intended not only to address the original reason for referral but also any other needs, either immediate or latent.

3.29 Also core to the Talking Points approach was the concept of regular review, ideally by the same care manager on an ongoing basis. As will be set out later, the review process was seen as important in ensuring that feedback was obtained from both service users and carers on their experiences of short breaks.

### ***Issues with identifying and measuring outcomes***

3.30 Although there was a recognition among most local authorities that Talking Points or similar approaches represented a positive way forward, there were also a number of concerns expressed. As one interviewee noted:

*"we are committed to an outcomes, not provision focus. The key is what difference has this made, but this is very challenging to measure".*

3.31 In a variety of forms, the issues of both identifying outcomes and measuring these was raised by a number of local authorities. A common area of concern related to what was seen as the "fundamental difference" between a volume-driven, nights-based approach, and one based in individual aspirations, which may be difficult to

aggregate. However, there was a recognition of the importance of aspirations and, one local authority noted in relation to measuring performance:

*“nights and hours are clearly important at one level, but service users’ aspirations need to be met and this causes a tension”.*

### **Carers’ assessments**

3.32 A number of issues were identified in relation to carers’ assessments. There was a consensus that these were a good thing in themselves, but it was clear that some local authorities had had more success than others in rolling these out and in promoting take-up.

3.33 It is worth noting that there were two basic approaches to assessing local authorities’ success. In some cases this was assessed on the basis of carers being given the *opportunity* to have an assessment, with some noting near 100% success in this, while other local authorities were more focused on the actual level of take-up. A point which was evident from interviews was that little information appeared to be available about typical levels of take-up across Scotland.

3.34 Among the local authorities which were able to provide specific data for this research, there was found to be considerable variation in the number of carers assessments carried out. Two neighbouring local authorities with similar overall population levels reported carrying out respectively 45 and 2320 carers assessments. Most reported between 50 and 200 assessments, with 2 (including the one mentioned previously) reporting over 1000. There was no obvious relationship between the size of the local authority and the number of assessments carried out.

3.35 In a small number of cases, the ability to carry out carers’ assessments had been vested in carers’ organisations, partly as a way of improving take-up, but also as a way of promoting an holistic approach to need. In other areas, it was clear that carers’ organisations had been involved in the development of assessment tools, or were otherwise very familiar with these, and could support carers in both preparing for, and responding to assessments. This role was very similar to that played by independent living organisations and Self Directed Support support services in supporting community care service users in preparing for single shared assessments.

3.36 One local authority noted a fundamental difference between community care and carers’ assessments, and echoed a point made by a number of interviewees, namely that carers’ assessments were neither a passport to services, nor were they required to access services.

3.37 Another local authority indicated that it had revisited its prioritisation system to help address what was seen as an in-built disadvantage to carers which made it relatively unlikely that they would reach the threshold to qualify for services in their own right. This point was echoed by a number of other interviewees as an area of concern.

## Emergency and crisis support

3.38 Two main forms of emergency or crisis support were identified. The first was where a client or carer was previously unknown to social work services and experienced a crisis. This would essentially be a new case for the service. The other was where a current client or carer experienced a change in their circumstances that made the planned care arrangement unsustainable.

3.39 The need for crisis support could arise where, for example:

- A cared-for person's health deteriorated, making it difficult for them to be managed at home.
- A carer's health issue arose which made it impossible for him or her to provide care.
- A family, work or similar situation arose which made it impossible (or very difficult) for a carer to provide care. A number of examples of this were identified as having arisen during the period of disruption following the eruption of the Eyjafjallajökull volcano in Iceland in early 2010.
- A cared-for person's house became uninhabitable on a temporary basis, for example as a result of a fire or water leak, or arising from scheduled repairs.

3.40 The basic processes adopted by local authorities appeared similar regardless of whether the support was required for a new or existing client, although some elements of detail may differ. The basic principle found to be adopted in all cases was that care should be provided quickly and ideally with neither interruption nor negative impact. Most local authority interviewees noted that care managers (or individual social workers in out of hours situations) would have delegated authority to arrange a short break without being required to go through normal approval processes, although retrospective approval may be required in some cases. It was suggested universally that this process worked well and few issues were identified.

3.41 Budgets generally did not appear to be an issue in relation to emergency or crisis support, and there was no indication that this would not be provided as a result of budgetary pressures or where other budgets were fully committed. Most local authorities identified that levels of crisis provision were similar each year and could be factored into budgetary processes. It was also suggested that the actual amount of emergency and crisis care was relatively small, at least compared to overall provision, and that, as a result, could be accommodated within mainstream (usually devolved) budgets. One interviewee suggested that:

*"we've looked year on year at where the hot spots are, and we have a pretty clear idea".*

3.42 A general view was higher levels of demand were experienced at specific times of the year, including Christmas and New Year, school holidays and periods of particularly bad weather.

### ***Reducing the need for crisis provision***

3.43 All of the interviewees indicated that steps were being taken to reduce the likelihood of the need for crisis or emergency provision. At a basic level, for example, it was noted that care managers targeted people known to be likely to be at risk of requiring emergency provision both generally and in the run-up to known stress periods to try to ensure that prior planning was undertaken. One interviewee also noted that staff meeting routinely with service users or carers were asked to look out for signs of breakdown. More widely, however, it was also suggested that improved assessment processes (described in more detail elsewhere in this section) could play a part in reducing the overall likelihood of care arrangements breaking down.

3.44 It was also suggested that the increasing use of telecare (again described elsewhere) could also play a part in reducing the reliance on emergency care, particularly where the system could be deployed quickly. It is also worth reiterating that some local authorities indicated that they were deploying telecare as a preventative measure, for example in cases where a carer had a health condition, both on a temporary and a permanent basis.

3.45 Clearly, the responses of local authorities in these situations related to the needs of the cared-for person and carer. As might be expected, these included: increasing levels of in-home support (e.g. through additional home carer visits; providing access to day care; a place in a care home or specialist unit. A number of interviewees stressed that removal of a client from their home was a last resort.

3.46 None of the local authorities interviewed indicated that emergency or crisis provision was a particular area of difficulty. It was acknowledged, however, that it may be difficult to quickly identify appropriate provision for some clients, particularly those with complex needs, especially nursing care. Other circumstances identified included situations in rural areas both where the nearest care home may be some distance away or where it would be more difficult to secure additional staffing through local authority or emergency routes. A small number of local authorities identified a specific difficulty where a request for emergency care may be the first contact with a client or carer. One NHS interviewee indicated that reducing the likelihood of this was one of the purposes of work being done with front line staff (including GPs) to help identify hidden carers.

### **Short Breaks Bureaux**

3.47 As set out earlier, there were a number of ways in which service users and carers could be supported with the organisation and management of their short breaks. In most cases, support would be provided by a care manager, but in a small number of areas this was undertaken by a Short Breaks Bureau.

3.48 The first Short Breaks Bureau was set up nearly 10 years ago. Although the basic concept remains unchanged, there have been changes to the detail of its services. In recent times, other Short Breaks Bureaux (or similar) have been established, largely following the original model, although in one case it found to work only with a single client group.

3.49 A more general interest in Short Breaks Bureaux had been identified by Shared Care Scotland. As a result, material on the concept and implementation was published, and an action learning set involving 9 local authorities facilitated. A number of other local authorities also expressed interest in the approach in general terms, or in adopting elements of it.

3.50 In basic terms, a Short Breaks Bureau acts as a broker for short breaks between either the service user or the social care manager and the provider of a break. Assessments remain the responsibility of the care manager in terms of, for example, whether a short break would be needed, and the number of nights allocated. The Short Breaks Bureau acts on referrals following assessment, providing both an advice service on suitable alternatives to meet the assessed need, and a booking service. Bureaux generally only provide support with out of home short breaks.

3.51 A number of advantages were identified for this model including:

- The centralisation of advice provision and booking allowed staff to become specialists in identifying appropriate short breaks.
- There was easier compilation and dissemination of feedback, thus making it more likely that poor experiences could be rectified, or that the provider was not used again.
- There was easier identification of new options for short breaks, in part as staff have the time and were empowered to identify new options. This was noted particularly in the identification of out of area options.
- There were savings for care managers allowing them to focus on other duties.

3.52 It was suggested that the model also allows for a more streamlined relationship with providers, as only one staff member would be required to carry out familiarisation visits. In some cases, the relevant staff member would also act as a conduit for non-contract issues such as identifying new services, the availability of staff with new skills, changes to opening hours etc.

3.53 From the perspective of providers, it was suggested that it could also be more efficient in terms of making local authorities aware of vacancies when a need for a crisis provision was identified. On the local authority side, it was also suggested that it may be easier to identify where vacancies exist, as these could be identified centrally and, as noted, may be communicated regularly by the provider.

3.54 As noted elsewhere, increasing personalisation particularly where this has led to families being enabled to holiday together, has meant that, in some cases, only a limited share of the overall cost of the short break could be met by the local authority. A further benefit of Short Breaks Bureaux identified by some interviewees was that staff gathered a specialist knowledge of other funding sources, for example, charitable trusts, and could advise on how to access these.

3.55 Overall, one of the key benefits identified was that service users would be more likely to receive a service tailored to their needs, not least as a Bureau removes the significant element of variability of knowledge and experience likely to

be present in front line social care staff. In essence, rather than dozens of social care staff being required to be familiar with hotels, B&Bs, specialist and non-specialist residential and care homes, as well as independent options such as bus tours or activity holidays, this knowledge would be centralised in a small number of staff. It was suggested that this approach would make it more likely that the goals of personalisation and dual benefit, at least in terms of out of home options, may be achieved. Clearly, if all care managers were equally knowledgeable, and had the time to make bookings, provide advice etc., the same level of benefit could be achieved through traditional routes.

3.56 The main stumbling block identified by interviewees in relation to the widespread adoption of Short Breaks Bureaux as a preferred model appeared to be cost. Additional costs would arise from the need for staff to provide the service and any office overheads, although proponents of bureaux arrangements suggested that these could be off-set by both greater efficiency and time savings elsewhere in the system.

3.57 One of the difficulties identified was that the original and longest established Short Breaks Bureau was created without any specific work having been undertaken in relation to cost and benefits. However, with the support of Shared Care Scotland, one local authority which had recently adopted a Short Breaks Bureau model agreed that its approval processes, including a cost-benefit analysis, could be documented and made available via the internet. At this stage, there appeared to be a low level of awareness of the existence of this material, but it is likely that this may prove useful to other local authorities in the future.

3.58 One local authority noted that work had commenced in its area to take the Short Breaks Bureau model further. At the time of writing, a brokerage model, operated by a national voluntary organisation under contract, was in development and will be piloted later in 2010, before being rolled out in due course. It was intended that the “brokers” would work with individual clients to develop tailored packages.

3.59 Finally, in relation to Short Breaks Bureaux and brokerage arrangements, this was identified as an example of good practice in relation to information sharing and joint working across local authorities. There was evidence of significant assistance having been provided to local authorities considering arrangements of this type, and a number of local authority staff had participated in the relevant action learning set facilitated by Shared Care Scotland.

### ***Information about short break options***

3.60 As noted earlier, the identification of short break options was generally undertaken by the social worker who carried out the assessment, or the allocated worker on an on-going basis. It was suggested by some interviewees that this approach relied heavily on the knowledge of the staff member about available options. It was also suggested (by social work interviewees, as well as those working in other types of organisation) that the options likely to be offered also depended on the willingness of the staff member to consider non-traditional options.

3.61 At a practical level, it was also noted that, in areas where this approach was followed, it may be very difficult to disseminate information about new options. Supporting this view, service providers (in an open forum setting) indicated that one of the main difficulties they faced in promoting new services was the number of individual social workers to whom information had to be provided.

3.62 In areas where Short Breaks Bureaux existed, to a large extent these issues were found not to apply. It was clear from interviews that, in these areas, social work staff either took advice from Bureau staff on options, or passed on responsibility for both advice provision and booking. In a small number of areas, even though a Bureau arrangement did not exist, a specialist member of staff, generally located centrally, was identified as providing either information or advice to front line staff. The centralisation of specialist information of this kind was identified as one of the key strengths of the Bureaux model.

3.63 At a national level, Shared Care Scotland has developed and maintains a web-based directory of short break options. This was re-launched in August 2010 as the "National Short Break Directory Service". Initially providers were identified by a search of internet sites, advertisements and directory entries, but, as the database became established, providers were more likely to approach Shared Care Scotland to ensure their details were carried. Access to the database is open to social work staff, although it was not clear how widely it has been used in the context of planning short breaks. Interestingly, use of the database was reported by both Short Breaks Bureaux and Self Directed Support support services involved in this research. The database is also used by individuals, including those using Self Directed Support or who are self-funding, as well as those wishing to take some measure of control of their care while still remaining within the direct funding process.

### **Self Directed Support and Direct Payments**

3.64 Self Directed Support (SDS) is a means of providing funding for people to arrange support to meet some, or all of their assessed community care needs, instead of receiving services directly provided by a public body. There are a number of elements to SDS, including: the involvement of the individual in the assessment of their needs; empowering the individual to identify ways of meeting these needs; providing a funding package (through a "direct payment" from a local authority or another funding stream); and enabling the individual to manage this themselves. Most people use the money to buy support from a service provider and / or to employ a Personal Assistant (PA) to meet their mainstream care needs, but many also use it to fund short breaks.

3.65 It is worth noting that there was a relatively low level of awareness among a significant number of interviewees about SDS (or about the use of Direct Payments). This included a lack of knowledge about levels of take-up, support available, and ways in which SDS might be being used to fund and manage short breaks.

3.66 Overall, there was a recognition that the number of people taking advantage of SDS was increasing, with most interviewees suggesting that this was a specific focus of the local authority. There was, however, some doubt as to whether short breaks was a key driver in this, recognising (rightly) that the focus of SDS was much wider, potentially embracing all aspects of a service user's care. There was a

recognition that, in most areas, the number of direct payments users may be increasing quite slowly. One interviewee noted that:

*“we are pushing SDS hard, but we’re not making much headway”.*

3.67 Others noted some difficulties with the use of direct payments (the most common form of SDS) for short breaks and this will be set out in more detail later.

3.68 Statistics provided by local authorities were interesting in showing the relatively low levels of use of direct payments for short breaks. Only in two areas (out of 15) did more than a quarter of recipients use this for a short break. In about half of the areas, the proportion was less than 10%. In 2 areas, none of those using direct payment had used this for a short break.

3.69 It was suggested by a small number of interviewees that the use of, for example, a Personal Assistant (PA) for mainstream care needs was either a form of respite in itself, or was a means of minimising the need for respite in the sense that the increased flexibility offered by this method allowed carers the opportunity to take part in social and economic activities.

3.70 In a small number of areas, sharp rises in the number of direct payments users were noted following tendering exercises either for specific services or specific client groups. For example, following a tendering exercise in one area, a significant number of service users had chosen to move to using direct payments rather than to the new service provider. It is worth noting that, in that case and, by extension, others, there had been little evidence of increases in the number of short breaks taken and little evidence that new SDS users were contacting nominated support services. The assumption made was that, in these cases, a direct payment had been a device to permit the re-engagement of a previous provider, rather than being a trigger for a reassessment of needs (for example using a Talking Points-type model) which could have led to an increased recognition of a need for a short break to be included in a care plan.

3.71 There was limited recognition of the use of direct payments to fund alternative types of short breaks although, as noted earlier, there also appeared to be a limited knowledge of SDS generally. However, where direct payments and, to an extent the Independent Living Fund, had been used over an extended period, there was some evidence of innovation among recipients. One interviewee suggested that service users were more likely to use direct payments for longer trips and particularly for independent family holidays. A small number of interviewees identified the use of direct payments to purchase support from agencies based in the holiday area, although it is worth noting that this approach was also identified as being used by directly-funded clients, particularly in areas with Short Breaks Bureaux.

3.72 It was also suggested that SDS users may be more likely, at least in some areas, to choose commercial service providers, such as caravan parks, hotels or B&Bs. One interviewee identified that, in their view, the recognition of how a direct payment could be used was, for some clients:

*“... like waking from a deep sleep”.*



3.73 A small number of examples were provided of individual cases where service users had benefited from increased flexibility through a direct payment, although, in fairness, similar examples were also identified by, for example, Short Breaks Bureaux, in relation to directly-funded clients. Some interviewees did highlight the issue of flexibility as being a main benefit, but it was also noted that able to cope with the administration may be atypical of what was seen as the majority of those with short breaks included as part of their care plan.

3.74 It was suggested by one interviewee that there may be merit in gathering examples of the ways in which direct payments have been used in order to help promote examples of good practice. Additionally, it was suggested by an external interviewee that there would be merit in gathering experiences from support providers in relation to the uses of this method to support short breaks.

3.75 It was also recognised that the changes to SDS as proposed in the recent Scottish Government consultation would be likely to have an impact on its use for short breaks, but it was viewed as being too early to say what the nature and extent of these changes might be.

### ***Support with SDS***

3.76 Across Scotland, a network of support services was identified for people who use SDS (or direct payments) as a route to managing their care. The main purpose of these support services was identified as being to provide assistance with practical matters such as administration, payment, recruitment and staffing. In relation to short breaks specifically, the research found that the range of services provided appeared similar, for example, in terms of matters such as negotiating charges with short break providers, providing advice on safe means of making payments, and ensuring that a proper record is kept of transactions and receipts.

3.77 However, it was identified that some support services would go further than this and provide additional support. Among the examples noted were:

- Supporting service users in negotiating entitlements with care managers.
- Helping secure external funding where a user or carer contribution was required.
- Advising on possible short break options.
- Securing feedback from users (generally) and carers (less usually) about their experiences.

3.78 The last two forms of support mentioned above were also identified as being provided by Short Breaks Bureaux where these exist.

### ***Difficulties for SDS users relating to short breaks***

3.79 It was suggested that those managing their own care may face a number of difficulties in relation to short breaks which were particular to this means of funding. These difficulties, drawn from a range of comments made by interviewees, are set out in the bullet points below and included that:

- Care managers may not always be aware of how short breaks should operate within a care package managed by the service user.
- In some cases, the care manager may be unaware of eligibility issues leading to short breaks not being included in a care plan.
- The delivery of a direct payment makes it difficult for some service users to afford either the fee element or the level of support necessary to benefit fully from a short break.
- Technical issues about the use of contingency payments, and policies in relation to clawback, can make it difficult for some service users to “save up” for a short break even where this is to be taken as individual “days out” rather than as a break.
- Service users may receive conflicting advice about which costs may be eligible. An example given related to the payment of transport costs to PAs, which may not be eligible in normal care situations, but which may be eligible where the PA was accompanying the client on a short break.
- Specific support in relation to the identification and booking of short breaks may not be available in some areas.

3.80 Overall, it was suggested that there may be positive benefits to SDS users from having access to an independent support service. It was also suggested that similar benefits would also be available to carers, particularly in cases where they managed the administration of a support package.

### **The use of telecare**

3.81 The increasing use of telecare solutions was identified. Broadly, telecare was identified as covering a wide range of technology-based applications located within an individual’s home in order to support them to live independently. Some, such as alarm systems triggered by a fall, have been used for many years and are well-established. Others were more recent and examples identified included motion sensors, water sensors, CO<sup>2</sup> detectors, smoke alarms, timers and door entry systems with remotely controlled cameras.

3.82 A number of demonstration sites were noted. One, for example, developed by a community safety partnership, had been built into an exhibition trailer and could be used in a wide variety of locations (such as gala days or open days).

3.83 One interviewee noted:

*“We’ve put a lot of emphasis on telecare, and provided a lot of funding to support this. I feel that this is very valuable – it can make a real difference in a lot of ways, particularly for a carer, who is given a higher level of reassurance that they can go out and take part in activities knowing that their family member is safe.”*

3.84 Clearly, there may be reasons for the use of telecare other than to provide a break for a carer, but it was clear that, for most, this was perceived to be a significant benefit.

3.85 A small number of interviewees argued that telecare should be regarded as a form of short break as it reduces the need for a carer to be present to monitor the risks to the cared-for person. Although it was seen as too early to be definitive, it was suggested that telecare appeared to be effective, at least when judged against the objective of making a service user feel safe.

3.86 Not all interviewees were positive about the benefits to the service user, although there was a high level of agreement about the level of benefit to the local authority as being relatively cheap to install, cheap to run and requiring relatively low staffing levels. The main concerns about telecare were partly ethical (in relation to the intrusiveness of the electronic monitoring arrangements) and partly psychological. The latter was founded in the concern that telecare often removes the need for some human interaction and may contribute to increasing levels of isolation among those using the system.

3.87 It was clear, however, that telecare has become a key element in providing respite to carers and that this is likely to grow further. It is worth noting that some local authority and NHS interviewees also identified a role for “tele-health monitoring”, again with a dual benefit identified in relation to easing the burden on a carer and promoting independent living.

### **The next section**

3.88 All of these findings have developed a picture of the local delivery process for short breaks, and a range of issues relating to this. The next section explores issues relating to demand, particularly from the perspectives of individual client groups before some conclusions are drawn in Section 5.

## **SECTION 4: THE NATURE OF DEMAND AND PROVISION TO SPECIFIC GROUPS**

4.1 A range of issues relating to demand and provision to specific groups were also explored in the research, and the findings of are discussed below.

### **Overall views of whether demand was being met**

4.2 It would be fair to conclude that most local authorities believed that most expressed demand<sup>16</sup> for short breaks was currently being satisfied. Within this, however, there were considerable variations by client group and, in some cases, by locality. Some noted that it was difficult to be definitive as supply and demand patterns changed over time. It was also noted that policy could change, for example, in relation to the application of eligibility criteria and the prioritisation process resulting from this.

4.3 It is worth reiterating that this assessment related only to meeting expressed or identified demand. As set out in Section 2, most local authorities acknowledged that there were likely to be areas of need which had not been identified.

4.4 Relatively few interviewees identified waiting lists to access any form of short breaks provision. The most common examples were waiting lists for some forms of specialised provision such as for adults with challenging behaviour, and also for day care, or where service users may be unable to travel readily to a facility with a vacancy. In one area (and perhaps more), those assessed as needing a short break could be fast-tracked for access to other services on a temporary basis, or could have immediate access to telecare, as a way of lessening immediate pressures when a preferred form of short break could not be made available.

4.5 The main areas of variation between local authorities were found to relate to perceptions of whether service users' aspirations in relation to the time and often the location of their preferred short break could be met. Generally, it was suggested that demand could mostly be satisfied at "off peak" periods, and particularly where a service user (and their carer in many cases) was choosing an assisted family holiday. However, it was less clear that choices could be satisfied at "peak" periods, particularly Christmas and New Year, Easter, summer holidays and the school October week.

4.6 It was also suggested that some providers, particularly in residential and care homes, placed what were seen to be unreasonable restrictions on service users, for examples, in relation to a need to book up to a year in advance. In some cases this was linked to changes in the balance of spot and block purchasing, and an overall reduction in the number of places available to local authorities at any one time. In this respect, a small number of interviewees were critical of some care and residential homes which, it was suggested, made it difficult to plan by withdrawing short break places at short notice when a long-stay client was identified. Others,

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<sup>16</sup> As noted earlier, for the purposes of this report, unmet demand is restricted to cases where an identified need cannot be met. Unmet demand does not, therefore, include, needs which have not yet been identified.

however, were more sanguine about this, recognising the financial pressures some providers may face.

## **Rural issues**

4.7 It was clear from the research that geographical factors played a part in both assessments and provision in many areas. Geographical issues impacted on all forms of provision, although most directly on those with a “bricks and mortar” element. Overall, however, it was clear that most local authorities struggled to provide, or could not provide, what one described as a “uniform pattern of service” across all locations.

4.8 The service identified as being least affected overall by geographical factors was day care for older people, although even with this, some service users may face significant journeys. In one area it was noted that work was being done to try to ameliorate this by setting up community-based, volunteer-run facilities in small rural towns and villages.

4.9 In-home services were also found to be virtually universal, but some difficulties were identified in relation to holiday periods, cover for staff absence and more generally where changes to the service were required. As with other forms of community care, including the recruitment and employment of PAs, service providers reported having only a limited labour pool to draw from in these situations. It was also suggested that options for service users may be more limited than in urban areas, for example in relation to choices about the timing of service delivery.

4.10 The main difficulties reported in rural areas related to specialist services. For example, in one area, it was noted that overnight provision for service users with dementia existed in one part of the authority, but that it was difficult for service users in other locations to reach them. Another local authority noted that:

*“... in a city there can be two centres, each easily reachable. Here, they might be 80 miles apart”.*

4.11 There were also general issues identified in some areas with residential and care home provision, particularly where only some service providers had invested in accessible facilities, or retained staff with particular skills.

4.12 It was also noted that smaller local authorities, or local authorities where clients were widespread, may be less likely to be able to provide or source short break facilities suitable for people with specific needs, for example relating to a physical or sensory impairment. This was seen as making it more likely that service users would have to travel out of their local authority area for a short break.

4.13 One local authority noted that geography may also play a part in other aspects of service users’ care. For example, in a large local authority, service users may have a choice of care manager, and may be able to have some influence over who carries out their assessment. In a rural area this was less likely to be practical. Also relating to assessment, it was suggested that service users in some areas may not have ready access to carers’ organisations which could provide advice on, or support through the process.

4.14 A range of views were offered about ways in which services in rural areas could be, or were being delivered. It was noted that increasing use was being made of telecare and, as noted above, steps were being taken to mobilise volunteers both to provide in-home breaks and to accompany clients on days out. Two local authorities identified changes to rostering patterns as a way of employing a team-based, rather than an individual worker-based approach. It was suggested that, where overnight provision was required, or where choices were limited, much more use could be made of accessible and appropriate guest houses, B&Bs and hotels, with additional support being provided where required. It was noted that this would also impact on the extent to which personalisation objectives could be met.

## **Transitions**

4.15 Issues relating to transition were also explored and this section will deal with two main areas of transition: between children's and adult services, and between adult and older people's services.

### ***Children's services to adult services***

4.16 There was a consensus view that the period of transition from children's to adult services could be difficult for both the young person and their family. The main areas of difficulty identified were that:

- Up to the age of at least 16 (and sometimes older), young people attend school and may be offered significant amounts of out of school activities. In some cases, young people may attend residential facilities. On reaching adulthood, young people may live with their parents 24 hours per day, particularly in cases where the young person cannot sustain work or a training place. One interviewee noted that "education isn't respite, but that's how it's seen".
- The volume of other supporting services for children and young people may be higher (for example those provided by health) than for adults.
- Some services which exist for children simply do not exist for adults. Others, which were free at the point of delivery for children, may be chargeable for adults.
- Young people, although only aged 18 or 19, may be placed in provision with adults who are much older, potentially leading to difficulties for both groups.
- Some young people with complex needs may require additional support to be provided in their homes, and this may be the first experience a parent would have of managing a care package.

4.17 A number of interviewees stressed that this was not only a period of transition for the young person, but also for their parents and wider family members. One interviewee summarised this in the following way:

*"As the young person gets older, the relative role of the parent changes. They move from being a parent, or parent carer, to being a carer, and this can be difficult".*

4.18 None of the interviewees indicated that, in their view, systems were in place to prevent any problems arising. Some suggested that problems were inevitable, regardless of how good transition systems were. Most areas, however, reported that work was being done to improve transitions, with examples including:

- The development of multi-agency planning, including education, social work and the NHS (and sometimes others) as well as the parents.
- The commencement of transition processes at an earlier stage (in some cases as young as 14).
- A focus on managing the expectations of families and young people of what adult services could offer.
- Putting in place a phased transition which allowed either children's services to continue for a period into adulthood, or a stepped access to adult services where appropriate to do so. Some also identified a key worker system.

4.19 It was noted that, in some areas, there had been a relatively high take-up of SDS as a way of managing care needs, including short breaks. The potential benefits of the early involvement of external services, such as supported employment providers was also identified, in order to maximise the opportunities for young people to secure training or work opportunities. It was suggested that this could reduce the potential need for short breaks at a later stage.

### ***Adult to older people's services***

4.20 Overall, fewer issues were identified in the transition between adult and older people's services. However, some difficulties were identified, including:

- Differing eligibility criteria for services e.g. day centres for disabled people up to age 65, but only for older people beyond 65.
- Differing funding streams.
- Differing levels and nature of provision.

4.21 It was noted that difficulties may exist for people who did not conform to "typical" patterns. Examples given included people with early onset dementia and people aged over 65 who acquired a physical impairment. The group identified most commonly as being ill-served, however, was people aged over 65 with learning difficulties. In some cases, this group may not be eligible to use facilities designed for younger adults, but equally may be unhappy in, or viewed as disruptive to the routine in a care home or day centre setting. It was also noted that older adults with learning disabilities who attended day centres as a means of providing respite to a carer may face antagonism from other service users.

4.22 At a basic level, it was noted that there may be significant disparities between care packages for adults and older people and, where an assessment has been carried out as an adult, a service user may have access to significantly lower levels of support (including short breaks) than had the assessment been carried out as an older person.

4.23 In some areas, however, it was suggested that few, if any, problems existed, and this was perceived to be largely as a result of the integration of adults and older people's services. In other areas, steps had been taken to ameliorate the difficulties by allowing a measure of flexibility in terms of both eligibility and funding over a much longer transitional period, which may extend to 70 or even 75 in some cases. In some areas, the number of people affected by these issues was relatively small, and it was suggested that, if necessary, problems could be addressed on an individual basis. One interviewee noted that:

*“We’ve had to put in place funding mechanisms to help people being disadvantaged – there’s been much head-scratching but we appear to be able to do this through services being flexible and being prepared to fund things outside normal parameters”.*

4.24 In other cases, where issues had arisen, local authorities were found to have changed eligibility criteria, for example to allow over 65s to attend specialist day centres for disabled people, delaying the point at which they would be expected to transfer to a day centre for older people.

### **Patterns of provision**

4.25 It was clear that there was no single overall pattern of provision that could be identified across Scotland. Although many common elements were identified, there were also wide variations. To some extent, provision appeared to be driven by supply and demand factors, but it was clear that strategic policy concerns also played a part in this.

4.26 In most cases, local authorities indicated that the overall pattern of provision was designed to meet expressed needs but also that they faced a number of constraints. A significant minority indicated that they wished to make more provision available, but were unable to do so, largely as a result of budgetary constraints.

4.27 Patterns of provision appeared to be as a result of a mixture of specific planning and organic growth. One interviewee suggested:

*“provision is a mix of what we’ve always done and new approaches we want to try out”.*

4.28 This view was typical of many expressed, although as will be set out later, there was evidence of significant changes to more traditional forms of provision.

4.29 It was also clear that many local authorities were in the process of considering the overall balance of provision made in the light of two main issues, personalisation and budgetary pressures.

### **Variation between areas**

4.30 As the tables in Annex 3<sup>17</sup> show, there is a very large level of variation across local authorities in terms of the total number of short break weeks offered, both for adults and for older people. While it is clear that statistical anomalies remain in the

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<sup>17</sup> Edited from the 2009-2010 Scottish Government Statistical Bulletin



ways in which the data is captured and presented, it seems unlikely that variations of this magnitude could be, in effect, attributable to data artefacts. Using total provision for older people as an example, the rates per 100,000 ranged from less than 4,000 weeks, to more than 20,000 weeks<sup>18</sup>. The relative rates for adults aged 18 – 64 ranged from less than 1,000 weeks to more than 4,000 weeks.

4.31 Data in the Scottish Government's statistical bulletin also suggests that there is a large variation among local authorities in terms of the relative balance of provision between day and overnight provision. Again, it is likely that some of the variation is due to differences in counting methods, but this cannot provide the whole explanation. For example, the share of total weeks' provision for over 65s accounted for by day services ranged from less than 20% to more than 80%. The proportions for adults aged 18 – 64 were similar.

### ***Common elements***

4.32 As noted above, a number of common elements were identified in the forms of provision offered by local authorities. At a basic level, three forms of short break appeared more or less universal:

- Overnight stays in a residential or care home setting.
- Specialist day centre provision.
- Various forms of in-home support.

4.33 Within these broad categories, however, there were wide variations in the precise nature of provision, with variations by area and by client group.

4.34 The statistical data provided by local authorities was interesting in showing the wide variation in the forms of short break provided. The sample was partial, with 13 local authorities being able to provide the information in full, but there was no reason to assume that the broad patterns would not be repeated. A table describing forms of provision is set out on the next page.

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<sup>18</sup> One authority reported a level of provision equivalent to nearly 70,000 weeks per 100,000 population.

**Table 2. Forms of short break provided**

Nature of provision	Number which provided or supported provision (n=13) 19
Breaks in specialist respite accommodation not attached to a residential care home	10
Breaks in specialist respite accommodation attached to a residential care home	10
Breaks in residential care homes but not in specialised respite accommodation	12
Holiday breaks (e.g. coach tours or mainstream hotel accommodation with or without additional support)	9
Breaks in the home of another individual or family	8
Breaks provided at home through a care attendant or sitting service	13
Supported access to clubs, interest or activity groups	8
Befriending schemes where volunteers provide short breaks	9
Day care	13

***Patterns of provision across groups***

4.35 A total of 15 local authorities were able to provide statistical data about the nature of the provision offered in their areas.

4.36 Local authorities provided information on the breakdown of clients by age, and gender. Not all were able to do this, as, surprisingly, some systems do not record the gender of the client as a separate field (and in one local authority, only some of this data was found to be complete). Among those that were able to provide a breakdown by age and gender, the findings were interesting.

4.37 The balance of provision between those aged 18 – 64 and those aged 65 and over was markedly different across Scotland. For example, in one local authority, adults represented only 9% of the beneficiaries of short breaks (with 4 local authorities in total identifying less than 20%), whereas, in two local authorities, more than 50% of beneficiaries were adults. The average among local authorities who were able to provide the data was just under 30%.

4.38 There were also marked differences in the patterns of provision by gender, both as a whole and within one of the two age bands. Among adults, the split in provision by gender was generally about even as might be expected. However, among over 65s, a large majority of provision was directed towards women (generally between 60% and 70%, reflecting the overall makeup of the population),

although in one local authority, only 31% of beneficiaries aged 65 and over were women.

4.39 Much of the data provided about individual client groups was hard to interpret as it was clear that there were two main approaches to recording across local authorities. Some clearly recorded only one impairment or condition, while others recorded all. For example, in some local authorities, older adults with a physical impairment would be recorded only as “older adults”, while in others, they would be classified as both an “older adult” and “disabled”. Clearly, not all systems were capable of allocating a “main” category, making it all but impossible to accurately provide a breakdown of most client groups. An illustration of this is that the reported percentage of beneficiaries with a physical impairment varied from 10% to 65%.

4.40 The data on both learning difficulties and mental health were likely to be more reliable, and showed marked differences between local authorities. Provision to adults with a learning difficulties ranged between 10% and 17%, with the exception of two local authorities where the relevant percentages were 32%<sup>19</sup> and 26%.

4.41 There were similar differences in the proportions of beneficiaries with a mental health condition. In two local authorities, this was as low as 2%, while in others it was generally around 7%-13%. However, in one local authority, the proportion of beneficiaries with a mental health condition was 20%.

4.42 Although the data was difficult to interpret, it is worth noting that some local authorities (which clearly used multiple categorisations) reported that between 25% and 30% of all beneficiaries had some form of dementia.

4.43 Issues relating to provision to specific groups are considered in more detail below.

### ***People with physical and sensory impairments***

4.44 The most common forms of provision for people with physical and sensory impairments were identified as being:

- In-home short breaks provided by an external service.
- Overnight short breaks in a specialist facility.
- Overnight short breaks in a care home or residential setting.
- Independent short breaks e.g. at a B&B or hotel.

4.45 There were mixed views about the most common forms of short breaks, suggesting that there was a variation by area. Generally, however, in-home short breaks was the type identified by the single largest number of interviewees. Specialist short break provision appeared to be relatively rare. A small number of local authorities were identified as running, or having access to, specialist units specifically for people with physical impairments.

4.46 A small number of condition-specific facilities were also identified, but these tended to be at least regional if not national in scope, and it may, therefore, be difficult for people in some areas to access these. The closure of one such facility

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<sup>19</sup> This was confirmed with the local authority concerned.

(Leuchie House in North Berwick, run by the MS Society) was recently announced, and concern was expressed by some interviewees about the longer term viability of others using a similar model.

4.47 It is worth noting that, in the view of a number of interviewees, people with physical and sensory impairments appeared to be most likely to consider using SDS as a means of managing their care, including short breaks. Clearly this was not uniform across Scotland, and may be related, as suggested by two interviewees, to the level of flexibility offered by the local authority.

4.48 Evidence was provided by local authorities and some external interviewees of the use of independent options, both using SDS and directly funded options as well as the Independent Living Fund in some cases<sup>20</sup>. Among the examples given were hotels, B&Bs, caravans, chalets, coach tours and activity centres. Although people with learning difficulties were also identified as using these options, people with physical and sensory impairments were generally regarded as the most likely to do this.

4.49 A variety of issues were raised in relation to short breaks and younger adults with physical and sensory impairments were among those more frequently identified as facing barriers. The most common issue identified for people with physical and sensory impairments was a view that it was difficult for this group to find appropriate overnight short break provision. In a number of areas, it was noted that there was no specialist provider and that the only other option would be a place in a care home or other residential setting. This was viewed by interviewees as inappropriate, and was also raised by a number of external interviewees as a key limitation for people with physical and sensory impairments. As one interviewee noted:

*“this is perhaps our most difficult area. We recognise that there is a lack of opportunity available to the group, and a lot of provision is unsuitable”.*

4.50 In one area, the only practical option for some people with physical and sensory impairments given the distances involved was identified as a place in a hospice.

4.51 It was also suggested that this group was most likely to require a booking to be made out of area, where local policies generally permitted this. Where this was possible, it was seen as a good option, but it was also seen as potentially expensive, incurring higher transport costs and potentially being time-consuming to set up in terms of negotiating and ensuring the appropriateness of support at the location. It was suggested by one interviewee that a Short Breaks Bureau would be better placed to do this than an individual care manager, and certainly, where Short Breaks Bureaux existed, this was a key strand of the provision offered to people with physical impairments.

4.52 A further issue raised was that people with physical impairments may face longer waiting times and less choice of location assuming they were not able to, or

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<sup>20</sup> It was also noted that some local authorities and support services also provided advice and, in the case of support services, a booking service to disabled people whose short breaks were self-funded.

prepared to use independent options. It was also noted by two interviewees that care managers may be more likely to wish to book these traditional options for this group, hence adding to the problem as there may be other, better options they were unaware of. Linked to this, it was also suggested by a small number of interviewees that people with physical impairments may be likely to receive fewer short breaks than other service user groups.

4.53 It was noted by some NHS and a small number of local authority interviewees that some people with complex needs may still be able to spend time in NHS facilities. While this would not be described as “respite” and would always be linked to a period of observation, treatment or rehabilitation, it was acknowledged that a practical outcome of this would be a break for a carer from caring. It was also suggested in two areas that facilities where there were GP-controlled beds may be more likely to be used in this way, although the evidence for this was purely anecdotal. However, an interviewee in another area noted that local managers had effectively ended this practice through greater scrutiny of admission criteria.

4.54 A number of interviewees (of various kinds) expressed frustration that some disabled people and their carers may be disadvantaged through being unable to access suitable nursing home provision even though appropriate facilities may be available in a local hospital. One interviewee suggested that some mechanism through which local authorities could “purchase” a short break bed could be helpful where no other suitable accommodation existed within reach of the client.

### ***Adults with learning difficulties***

4.55 The most common forms of provision identified for adults with learning difficulties were:

- In-home short breaks.
- Overnight short breaks in a specialist facility.
- Independent short breaks.
- Day short breaks via volunteers or support services.

4.56 It was noted by a number of interviewees that the overall volume of short breaks taken by adults with learning difficulties had increased sharply in the last ten years following the closure of a number of residential units. It was suggested that a significant amount of support had been provided to families affected by this, and that the need for short breaks had been seen as a key element of the care plans put in place.

4.57 There was evidence, however, that provision was not uniform across Scotland, with, for example, specialist residential units existing in only a limited number of areas. Interviewees suggested that, where no specialist provision existed, use was generally made of either block or spot purchase arrangements to source provision in other areas.

4.58 Specialist residential units were identified as taking a variety of forms, including both purpose built blocks with a number of rooms, community-based flats or houses, and, in a small number of cases, beds within a care or residential home

setting where staff have specific skills and expertise in working with adults with learning difficulties.

4.59 In one area, it was identified that agreement had been reached to provide a total of 8 units for adults with learning difficulties within a new housing development. A further two units were identified as being available for short breaks. The development was intended to have support structures in place which would benefit both residents and those taking a short break.

4.60 One area specifically (and others by implication) operated a core and cluster approach to provision, where a number of adults with learning difficulties could be supported from a central point while living or taking a short break independently.

4.61 Relatively few specific issues were identified by local authority interviewees in relation to provision for this group, although it was recognised that they could face some barriers<sup>21</sup>. There was little evidence presented of significant delays or constrained choices, and none of the interviewees raised issues in relation to placing adults with learning difficulties in unsuitable settings.

4.62 A number of examples were provided of ways in which more flexible provision had been used as a means of delivering greater levels of personalisation. In a number of areas, local authorities reported developing options, generally with the voluntary sector, which provided either paid staff or volunteers to support adults with learning difficulties to undertake mainstream day-based activities. Clearly, the benefits of this went beyond simply providing a break from caring, but it was indicated that this was a key element.

4.63 In one area, the local authority reported the development of a pilot programme designed to bring the benefits of SDS without the “burden” (or responsibility) of managing a direct payment. This would allow the adult with learning difficulties to book a break with the local authority meeting the cost, without other aspects of their care changing. In other areas, it was noted that adults with learning difficulties were making increasing use of SDS as a way of managing all aspects of care, not only short breaks.

4.64 One interviewee reported that their local authority had created a Short Breaks Bureau specifically for this client group, while another was considering this. Clearly full service Short Breaks Bureaux in other areas also work with adults with learning difficulties. One interviewee suggested that there were a “whole raft” of options not presently suggested to, or used by adults with learning difficulties and, by extension, that could be identified by and provided through a centralised specialist service.

4.65 A key difficulty identified was that some adults with learning difficulties live with older carers. This was seen to present a longer term concern about what may be required once these carers are unable to provide support. However, in the short term it was identified that this may require the use of short break options which do not involve other family members.

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<sup>21</sup> It is worth bearing in mind that this research focused on the views of providers, and it is recognised that service users’ views may be different.

4.66 As noted above, some options were identified which allowed access to, for example, activity holiday centres, but, in addition, it was noted that adults with learning difficulties were making more use of both SDS and other means to take breaks with a companion who may be a PA, or who may be an employee of, for example, a specialist national voluntary organisation.

4.67 Overall, however, it was acknowledged that not all adults with learning difficulties would wish, or could cope with independent, or holiday-type breaks. For these reasons, it was suggested that there would be likely to remain a need for both in-house and specialist residential unit-based forms of provision.

### ***Older people***

4.68 The main forms of provision identified for older people were:

- In-home short breaks.
- Residential breaks in a care home.
- Day centres.

4.69 In addition, specifically for older people with dementia, a number of interviewees mentioned specialist units, or specialist beds in care homes.

4.70 Most local authorities indicated that while older people requiring a short break were relatively easy to place, they also represented the greatest area of concern in the medium to long term. It was noted by one interviewee that:

*“... it’s a large group and it’s getting larger”.*

4.71 It was noted that this has placed considerable pressure on both provision and, at a wider level, budgets.

4.72 It was also suggested that this group was likely to have the highest levels of unmet need, largely as a result of two factors:

- Many older people do not regard themselves as carers.
- Many older people requiring care do not seek short breaks as they assume these would have to be taken in a care home.

4.73 It was noted that, in relation to hospital discharge, many older people who would otherwise be likely to be assessed as requiring care (and short breaks) decline this. Overall, therefore, even though the actual level of demand from older people was high and, in some areas, presenting difficulties, it was considered to be likely to rise further, not only as a result of demographic changes, but also as a result of work to identify hidden carers, and particularly of moves towards greater personalisation.

4.74 Most overnight provision for older people was identified as being in care homes and nursing homes. Provision was identified as being spread between local authority, private and public sector ownership. It was clear that, in most areas, there was still a considerable reliance on block-booked beds, even in areas with a strong commitment to exploring non-traditional options. This was seen by some as essential to their overall service, and was identified as a means of helping families to exercise

greater choice in terms of date and location. Some identified that this was consistent with personalisation, as a care home bed was the preferred option for the cared-for person and the carer. It was seen as safe, “known” and most likely to deliver a stress-free experience for both parties.

4.75 In addition to block purchase, virtually all local authorities identified spot purchasing beds in care homes and similar facilities. This option was seen as offering better value, as only beds actually required were paid for and discounts could sometimes be negotiated for filling spare capacity, but at the expense in some cases of allowing older people and carers flexibility in terms of timing and location. It was also suggested by a small number of interviewees that spot purchased beds were less reliable as these may be more liable to cancellation if a provider was able to secure a long term resident.

4.76 It was acknowledged by some local authorities and some external interviewees that a residential bed may not be viewed as ideal, or even acceptable by some older people and / or their carers.

4.77 It was identified that some feedback on care home provision had been negative, with suggestions of, for example, a lack of things to do, uncertainty over medicines and issues with the mix of residents. As noted elsewhere, all local authorities had some form of feedback in place, even if this was part of a periodic review of a care plan. It was suggested that significant concerns could be identified by this means, and would be raised with the provider.

4.78 However, some external interviewees noted that older people remain very reluctant to complain, in part due to concerns about losing entitlements, and in part for fear of poor treatment if they had to use the same facility again. This was identified as a particular concern in rural areas where there were generally fewer options, or where the cared-for person’s needs were specialised. Some carers’ centres and SDS support services were identified as providing a neutral third party route to raising concerns.

4.79 Some local authorities indicated that they had tried to move away from “traditional” overnight short breaks, partly by identifying alternatives and partly by seeking to educate both care managers and service users, as well as their carers. It was suggested that these efforts had not always been successful, largely as a result of what was viewed as “conservatism” on the part of service users and carers and, to some extent, care managers. It was also noted that older people, and particularly older people with dementia, were among the groups least likely to use SDS to manage their care, again making it correspondingly less likely that they would use non-traditional short break options.

4.80 A number of local authorities mentioned specifically trying to move to an outcome-focused approach for older people, recognising that much current provision was volume-driven with corresponding nights-based targets. However, it was acknowledged that this may not actually bring about any significant change in the pattern of provision in itself without additional work to develop credible alternatives.

4.81 There were a small number of examples provided of overnight provision for older people away from care homes, for example in sheltered housing complexes or,



in a few cases, hotels with appropriate support. Overall, however, provision to this group was the least likely to demonstrate innovation.

4.82 All local authorities provided in-home short breaks, although there was not always agreement on what support should be included within this definition. Some local authorities suggested, for example, that, for some people, even home care could constitute a short break. This view was rejected by one interviewee on the basis that home care would be unlikely to be identified in a care plan as providing such a benefit and by another as the duration of a home care visit would generally be too short to allow a meaningful break for a carer.

4.83 As noted elsewhere, most local authorities reported substantial increases in the use of telecare. Again, there were mixed views about whether telecare could be considered as providing a break from caring. Some believed it did, while others suggested that the focus should be more on benefits relating to the safety of the cared-for person and that providing a break from caring was incidental.

4.84 In most areas, local authorities were identified as contracting with one of a number of specialist providers to provide in-home care for older people, particularly older people with dementia, where a direct benefit was to provide a break from caring for their carer. Clearly, many older people living alone also receive a service of this type. Some of the providers identified by local authorities were specifically focused on older people with dementia, while others had a more general remit.

4.85 The other main form of provision identified for older people, including older people with dementia, was day care. It is worth bearing in mind that many older people would receive both in-home care and day care, and this was described by some interviewees as a “typical combination”. As with other forms of day-based provision, there were mixed views of the extent to which day centre attendance constituted a short break for a carer from caring.

4.86 Most interviewees indicated that day centre provision was well-used and that, in some locations, could have waiting lists. To try to address this, a small number of local authorities indicated that eligibility criteria were being tightened and that day centres would no longer be regarded as a form of universal provision.

4.87 It was acknowledged that the changing pattern of attendees could cause some level of tension within day centres. Typically, patterns of attendance were identified as becoming more weighted towards older people with dementia, and this was seen to have made the provision of group activities more difficult. As noted earlier, day centres have also had to make provision for increasing number of adults with learning difficulties, again making it more difficult to provide group-based activities, and placing more pressure on staffing levels.

4.88 One area identified that it operated a “mini” Short Breaks Bureau for older people, in effect a worker whose role included the organisation of breaks which were non-traditional in nature. Areas with full service Short Breaks Bureaux were also found to be seeking to expand the options available to older people, again with mixed success. One area had had some success in using SDS, but recognised that by no means all older people could cope with the administration involved.

4.89 In summary, mainstream provision to older people was characterised as being “risk averse” and very traditional. One interviewee noted that:

*“older people are very fond of buildings”.*

4.90 In most respects, provision for older people with dementia was found to be similar, although a number of interviewees recognised that the issues for carers in terms of, for example, willingness to take a break at all, were often even more intense. People with dementia, and particularly early-onset dementia were identified frequently as experiencing specific barriers. Although issues were seen to remain, however, for people with dementia, one interviewee noted:

*“thank God things have moved on from two weeks in a psychiatric ward”.*

4.91 A number of issues were identified specifically in relation to dementia, including that:

- Adults with early-onset dementia may find it difficult to access services as they would be likely to fall outside general eligibility criteria. A number of interviewees mentioned that specific flexibilities had been put in place to deal with this group.
- In some areas, there was a lack of specialist provision. It was also noted that some providers advertising as being “specialist” in fact lacked the depth of skilled staff to provide 24 hour cover for older people with dementia.
- There were mixed views about care at home. Some saw it as best, while others identified issues, for example, with the carer being reluctant to treat the care period as an opportunity for a “break”. It was also noted that such a service may be expensive.
- Very little suitable provision was identified in the private sector to support independent breaks. Only one local authority identified this as being available, and then only on a very limited basis<sup>22</sup>.
- As noted above, some day services were reported to find it difficult to cope with increasing numbers of older people with dementia.
- Clients in rural areas may find travelling to specialist facilities difficult, although one example was identified of provision developed by a local community to prevent island residents from having to travel to the mainland.

4.92 In many areas, dementia strategies had either recently been produced, or were in preparation. Issues for carers were identified as being a significant concern in these strategies although it was also suggested that short breaks from caring may not be covered in detail.

### ***People experiencing mental health problems***

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<sup>22</sup> One interviewee reported that an accommodation provider in a rural area had begun to advertise short breaks specifically for older people with dementia, although at the time of writing, they were unaware of any clients having used this.

4.93 The main focus of provision identified for people experiencing mental health problems was:

- Specialist day services.
- Flexible breaks with support.
- Breaks at centres run by national voluntary organisations or flats managed locally.
- Some home-based short breaks.

4.94 A number of interviewees indicated that adults experiencing mental health problems were among the groups most likely to face barriers to obtaining short breaks. In some areas, this appeared to be as a result of short breaks being restricted to adults with a carer living in the same house. More generally, a number of interviewees indicated that people experiencing mental health problems were perhaps least likely of all groups to take up short breaks. In some cases, this perception had been supported by statistical analysis undertaken by the local authority. It was also suggested that, as many people experienced fluctuations in their health, the actual process of arranging and supporting short breaks could be very difficult.

4.95 There were also mixed views about the nature of services actually required by people experiencing mental health problems. A small number of interviewees, for example, questioned whether some people in this group actually wanted a period away from home, or would be likely to benefit from it. Other interviewees, however, were more positive.

4.96 By far the most common form of support for this client group was identified as being specialist day services. Some interviewees questioned whether this should be viewed as respite, but others were less concerned, viewing this as an outcome for the service user's carer and family. A wide variety of such facilities were identified, some run in conjunction with the NHS, some through voluntary organisations.

4.97 A small number of areas identified that some form of flexible short break provision, generally with support, could be made available. One local authority identified that it ran a short break scheme specifically for people experiencing mental health problems. Another local authority noted using Mental Health Act monies to support some people experiencing mental health problems to access B&Bs with some external support. A third area noted that it was about to pilot a closed voucher scheme involving three providers offering flexible short breaks on a call-off basis.

4.98 Two areas noted that specific provision had been made available through carers' centres for carers of people experiencing mental health problems. One identified that it was considering the idea of group holidays, another that it was providing relaxation therapies for carers of this group.

4.99 A further issue noted by some interviewees was that few people experiencing mental health problems appeared to use SDS as a means of managing their care and, within this, short breaks. It is worth noting that few local authorities appeared to view developing the use of SDS by this group as a specific priority. The perceived difficulties posed by people's often chaotic lifestyles and fluctuating conditions were highlighted.

## ***Ethnic minority clients and carers***

4.100 There was some recognition that there may be specific issues for ethnic minority clients and carers in relation to short break provision. It was also acknowledged that ethnic minority clients and carers may be likely to face a wide variety of barriers in both finding out about, and gaining access to services. One interviewee noted, for example, that information about short breaks was routinely published in English with a short section suggesting that it could be translated on demand. However, it was suggested that the distribution arrangements for these publications meant that they were unlikely to be seen by people whose first language was not English.

4.101 Some interviewees acknowledged that their local authority had done little to address issues for ethnic minority clients and carers specifically. As might be expected, there were also varying views about the frequency and extent of issues arising for ethnic minority clients and carers. It would also be fair to suggest that monitoring remains very patchy. Some local authorities were unable, for example, to give any detailed breakdown of the number of cared-for persons taking short breaks by ethnicity. A number acknowledged this as a specific weakness. It is also worth noting that, for practical reasons, a number of local authorities appeared to regard people from Eastern Europe as an ethnic minority group.

4.102 There were a small number of examples of specific engagement with ethnic minority clients and carers. These had produced varying results, with one area reporting that the consultation had suggested no specific requirement for anything other than mainstream services, while in another area the opposite outcome was identified. Some interviewees acknowledged what was described as a “debate” about how to provide services to ethnic minority clients and carers.

4.103 Regardless of this, there was a clear recognition of the need to provide services which were culturally competent and two basic ways of addressing this were identified. In a small number of areas, local authorities reported contracting in services from specialist providers. This was, however, relatively rare, and in most cases the main focus was on providing training to front line and management staff.

4.104 Only in larger areas was there evidence of systematic and structured provision. In most areas, a reactive approach was noted, where issues were identified through an assessment process. It is worth noting that there was also a general willingness on the part of some smaller central belt local authorities to purchase services from specialist providers based in the cities.

4.105 A number of specific initiatives were noted which included:

- Work with a migrant workers’ service to try to ensure that hidden carers were identified.
- A self-assessment pilot using translated forms.
- Efforts to recruit workers from ethnic minority communities into services.
- A specific residential unit for a Chinese community.
- A small network of group-specific day centres with extensive use of transportation to get people to these centres.

- Outreach work and a carers group specifically targeted at ethnic minority communities.
- An information worker shared with the NHS to provide support to both Eastern European and Asian communities.
- Lunch clubs (although the “short break” value of these was not clear).
- Attempts to increase take-up of SDS.
- The use of in-home short breaks, as residential services were not viewed as culturally acceptable.
- A needs mapping exercise by ethnic group.

4.106 Overall, there was mixed evidence of specific work to address the needs of ethnic minority clients and carers. Interestingly, however, there was a clear view that this was an issue, with an expressed willingness to engage with ethnic minority communities. In some cases, this was being done directly with ethnic minority clients and carers, in others via representational structures. One local authority identified having carried out an Equality Impact Assessment on short breaks services which was seen as valuable, and it may be that others have also done this.

### **Other groups facing barriers**

4.107 It was clear from the exploration of the nature of demand and provision to specific groups that there are specific patterns and issues for difference client groups as well as common issues in relation to short breaks planning and provision.

4.108 A number of barriers have also been identified and, in addition, it was note that people with difficult or challenging behaviour were seen to face barriers regardless of their client group. At a more general level, it was noted that some groups faced effective barriers as they were seen to be less likely to be able to cope with the management burden of SDS. Finally, as set out earlier, service users in rural areas, regardless of client group, were seen to be likely to face barriers.

### **The next section**

4.109 Some of the key conclusions which can be drawn from the research are brought together in the final section.

## **SECTION 5: CONCLUSIONS**

5.1 The previous sections have set out firstly the background and context for the work, then the main findings from interviews with local authorities and others, and the statistical survey. This section will draw together these findings. The final section will offer a small number of suggestions for further action.

5.2 The research identified clearly that there are a substantial number of people working to make short breaks effective for both carers and carer for persons, as well as efficient in relation to delivery. The level of commitment shown is considerable, and this should be acknowledged.

### **The wider context for short breaks**

5.3 Before considering the key issues, it should be noted that, although the report describes issues specific to short breaks, it is important to set this in the wider context of both public sector budgetary pressures and the National Carers Strategy.

#### ***Funding pressures***

5.4 The issue of funding was identified as relevant to short breaks by virtually every interviewee, although none was in a position to know how this might impact on provision in the future. There was a widespread view that cuts appeared inevitable, both in terms of short break provision and in the allocations provided both to carers' organisations and support services. A small number of interviewees suggested that there was evidence of cuts already being made in some areas, with a presumption that more would follow.

5.5 It is important to bear in mind that much of what is set out below in relation to good practice in the planning and delivery of short breaks, as well as most of the suggestions for action at the end of the section, would be contingent on budgets being adequate.

#### ***The National Carers Strategy***

5.6 The National Carers Strategy was launched on 26<sup>th</sup> July 2010 and contained a chapter on respite and short breaks. The key actions points within the chapter are set out in Annex 2. Each of these is also likely to have a significant impact on the future shape of short breaks provision. It is clearly too early to say how the £5m over 5 years will be used, or to assess the impact of the ending of additional funding to local authorities. A further indirect impact of the National Carers Strategy is likely to be an acceleration of the development of, or updating of local carers' strategies. A number of interviewees indicated that the publication of the National Carers Strategy would be the trigger for work at a local level.

#### **Key issues in relation to short breaks**

5.7 Against this background, the first part of these conclusions deals with the key findings within the report on a range of aspects of short breaks provision across Scotland.

## ***Arrangements for management and delivery***

5.8 The overall arrangements for the management and delivery of short breaks have been found to vary considerably across Scotland. It would be fair to suggest that no two authorities were found to be the same and that there were, in effect, 32 different strategic approaches, and 32 different management and delivery structures in Scotland. To a large extent, this could be considered unsurprising, as, for example, the ways in which social work services, and increasingly, health and social care services are structured also varies.

5.9 Whether the variety of approaches causes any particular problems is a moot point. Markedly different strategic and management approaches (with varying levels of engagement) appeared to produce similar patterns of provision, and conversely, outwardly similar management arrangements were found to produce markedly different forms of provision. However, there is no doubt about the level of variation.

### *Strategic approaches*

5.10 Although the Scottish Government Guidance recommended the development of a free-standing or summary strategy for short breaks, the research found that relatively few local authorities and their partners have chosen to do this. In some cases, local authorities expressed direct opposition to this approach. Only a small number identified an intention to develop a free-standing strategy in the near future.

5.11 At a broad level, most local authorities identified that their overall direction in terms of social care generally, and short breaks specifically, was provided by, for example, their Single Outcome Agreement, Community Plan or Joint Community Care Plan. A sample of these studied for this research suggested that very few actually mentioned short breaks directly, although there was more focus both on the needs of carers and on the issues facing equalities groups generally.

5.12 A number of local authorities also suggested that some strategic direction was provided by service improvement plans, or departmental strategic plans.

5.13 At an operational level, work relating to short breaks was most commonly found to be located within the context of a carers strategy and there was a clear view from many local authorities that this was appropriate. In some cases, part of the strategic context was also provided by client group-specific strategies.

5.14 A number of local authorities identified that they intended to revisit their carers' strategies, and, through this, their strategy on short breaks, once the National Carers Strategy had been published.

5.15 It was clear from a review carried out for this research that a significant number of these strategies were out of date, at least in the sense of their having passed their nominal "end" date. Again, the extent to which this was a problem at an operational level is moot, as there was no evidence of any specific consequences arising from not having an up to date strategy, for example, in terms of work being discontinued, or development work being suspended. Some of the areas which were able to demonstrate innovation in service delivery were among those with out of date

strategies. However, in terms of the overall message given, the existence of an out of date strategy could be seen to provide a less than positive message.

5.16 Additionally, arguably the lack of a clear strategic context could cause difficulties for local authorities or partnerships seeking to establish the effectiveness of their provision. Many local authorities identified work on outcome-related assessment and review processes for individuals, and it would be logical that these should be rooted in, or linked to wider outcomes for the service established as part of the wider move away from assessing performance purely by volume measures. Without a strategy, or an up to date strategy, it is difficult to see how this could be done effectively. More widely, it would clearly be very difficult for any local authority without an up to date strategy to carry out any evaluation or structured assessment of the effectiveness of their short breaks provision.

5.17 The other area in which the lack of a strategic context for short breaks could prove problematic is where local authorities are reassessing the balance of their provision in the light of budgetary pressures. A number of interviewees suggested that there would be a danger that this was done in an ad hoc and piecemeal way unless there was a clear strategic context for short breaks, with objectives and service level outcomes, to guide these considerations. As one interviewee noted:

*“It is easier to argue the case for short breaks when you can point to your objectives and show how you are meeting them.”*

5.18 It was suggested that there was also a need for a clearer understanding of the benefits and costs of short breaks, particularly when compared to other forms of social care provision, particularly, as might be expected, long term residential care and emergency admission to hospital, as well as an increased requirement for health and social care services for carers.

5.19 A consistent issue raised by local authorities considering Short Breaks Bureaux (or similar approaches) was a lack of a clear cost-benefit framework to support the assessment process.

#### *Equality Impact Assessment*

5.20 Only one interviewee mentioned having undertaken an Equality Impact Assessment in relation to an aspect of short break provision (although it is possible that others had, but did not mention it). There is a clear argument that *all* aspects of short break provision should be regularly reviewed using an EQIA process given the nature of the client groups who benefit from short breaks.

#### *Management responsibility*

5.21 Management responsibility for short breaks was found to rest firmly with local authorities, or, in a small number of cases, merged health and social care teams, although, in one case, it was suggested that, even where services had been merged, there appeared to be little involvement from health staff.

5.22 As with overall strategic direction, there was evidence of a wide variety of management arrangements within local authorities. In a small number of cases, a



single manager was identified as being responsible for all short breaks, but in most cases, this was devolved by client group. Thus, for example, the manager for older people's services would generally be responsible for short breaks for carers where the cared-for person fell within their client group.

5.23 There was evidence of a range of decision making processes in relation to the approval of short breaks. In some areas, these decisions were found to be devolved to a care manager, while in others, to assessment panels. No particular issues were raised with this, and it was clear in all cases that, where emergency care was required, these processes could be either truncated or by-passed, with, for example, retrospective approval being given where a care manager had been required to purchase a service at short notice.

### *Engagement*

5.24 It was clear from this research that there was a significant amount of engagement between statutory partners and carers and carers' organisations. A number of weaknesses in this were identified, both by local authority and external interviewees, but it appeared that there was a general willingness on all sides to work in partnership.

5.25 The commitment to partnership appeared, in most cases, to extend to strategy development, and groups taking a strategic overview of planning and provision. It is also clear that there was evidence of a great deal of day to day working extending in some cases to devolving budgets for small scale short provision, or extending the right to carry out carers' assessments. It was also clear that carers' organisations mainstream work with carers was viewed as critical in helping ensure that carers remain able to care for their family member.

5.26 At the level of individual carers, structured engagement was found to be undertaken largely by carers' organisations, although some local authorities appeared to be more proactive, particularly in relation to strategy development.

5.27 Some notes of caution were sounded by external interviewees and by some local authorities in relation to engagement.

- The longer term funding climate remained uncertain, and it was not clear what impact this may have on carers' organisations.
- The pressures placed on carers' organisations have increased significantly in recent years, and some may be likely to find it difficult to fulfil all of the roles expected of them without specific funding. It was suggested that this may be difficult particularly in areas where strategic forums exist for each client group and on which carers' representatives would be expected to sit.
- A risk that, as some local authorities devolve funding and, for example, responsibility for carers' assessments, the nature of the relationship may change, and carers' organisations may come more

to be regarded as sub-contractors or service providers than strategic partners<sup>23</sup>.

5.28 It is worth noting that the level of engagement with independent living organisations (as an umbrella term for organisations of and for disabled people) appears more patchy. In many local authorities, short breaks work was found to be rooted within a carers' context, although it is likely that, at the level of individual client groups, there may be more engagement. Given that Scottish Government guidance is focused upon dual benefit, this is perhaps a surprising finding.

#### *Eligibility criteria and prioritisation processes*

5.29 Although an examination of eligibility criteria and their application was beyond the scope of this research, issues with this were raised both by local authority and other stakeholders. It was suggested, for example, that many clients who might benefit from access to a short break were unable to access one as their needs were not assessed as critical or substantial. It was also noted that the application of eligibility criteria was being tightened, at least in some areas, in part as a way of prioritising scarce resources through ensuring that only the highest priority clients would be deemed to be eligible.

5.30 There did not appear to be a direct link between the level of assessed need for a community care service generally, and the need for a short break. Thus, for example, a client may be assessed as requiring a large package, but their family may have relatively little need for a short break. Conversely, some carers most at risk of a physical or mental health-related breakdown may not be able to access a short break as their cared-for person was not assessed as a high enough priority to access a community care service in their own right, even though a carer's assessment demonstrated that the carer had a need. This issue may become worse as local authorities tighten overall eligibility criteria.

5.31 It was suggested that one way of addressing this would be for carers to be able to access community care services *as carers* in their own right. However, current prioritisation procedures would also have to be changed, as carers, even where a need was assessed, would be unlikely to achieve a high enough level of priority to gain access to a service.

#### ***Personalisation, assessments and an outcome focused approach***

5.32 Clearly, the reach of personalisation extends far beyond short breaks, but it was clear from the research that it was having a considerable impact on both planning and delivery of short breaks within many local authorities. This was manifest in a number of ways, including an increasing focus on identifying outcomes within the assessment and review process, and in helping families secure short breaks which are better tailored to their needs.

5.33 As might be expected, there was little variation the ways in which the need for short breaks was identified. In virtually all cases, it was identified that this was

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<sup>23</sup> In fairness, no specific examples of this were provided, but it was noted that many local authorities did not engage routinely with social care providers in relation to strategy or policy matters in order to avoid allegations of unfair advantage.

carried out as part of an assessment of the needs of the cared-for person and, increasingly, the carer.

5.34 However, a significant number of interviewees suggested that the key issue with assessment was not the process but rather the level of variability in the knowledge and understanding of individual assessors about short break options. It was clear from the research that significant difficulties exist in making assessors (regardless of their role) aware of new options, or in keeping them up to date with both changes in current provision and any quality issues which arise. It was suggested that this has an impact on progress towards personalisation, and may have the effect of perpetuating the use of traditional options where these are neither the best option for the client, nor the most cost-effective option for the local authority. Shared Care Scotland launched a new version of its short break database in August 2010, but it was not clear how much use is made of this by frontline staff. In areas where a Short Breaks Bureaux arrangement exists, these issues were found to be much less likely to arise.

5.35 Most local authorities reported some success in rolling out carers' assessments. In a small number of cases, the ability to carry these out has been devolved to carers' organisations, but most remain the responsibility of social work staff.

5.36 It was clear from the research that a number of local authorities have been working, largely independently, on improving both single shared assessments and carers assessments, with a view to linking these more closely to outcomes and, in some cases, to make them more transparent and less time-consuming (or complicated). It was suggested that it would be useful if more work of this kind could be done at a national level, or at least on a cooperative basis across local authorities with the involvement of others where appropriate.

5.37 As well as seeking to have a focus on outcomes, other work was identified which would simplify the process. In a small number of areas, carers' organisations were found to have been given delegated authority to carry out carers' assessments.

5.38 A number of issues were also identified in relation to personalisation. The first was that the pace of change, and progress generally, was highly variable. Some local authorities reported significant progress towards adopting outcome focused assessments, while others clearly had made less progress. Linked to this, it was clear that there were a range of different approaches being developed. There was some co-operation at a national level, but a number of interviewees specifically suggested that it would both be more efficient and more effective for work relating to single shared assessments, and the embedding of outcomes, to be taken forward in this way.

5.39 Some areas were found to have adopted the Talking Points framework, but even within this, it was suggested that there may be significant variations between local authorities in how, for example, assessments were constructed. It was also suggested that even within a framework such as Talking Points, there was considerable scope for additional work to help local authorities design respite and short break specific outcomes which were more personal and meaningful to clients and carers.

## *Measurement*

5.40 One of the most consistently identified problems facing local authorities appeared to be that of measurement. There were two clear but linked issues relating to this. The measurement of volume and the measurement of outcomes.

5.41 In relation to volume, it is clear that this has been a difficult area for both local authorities and the Scottish Government over the past few years. Originally Audit Scotland and now the Scottish Government sought to bring some consistency to both measurement and reporting, but this has proved difficult, with, as noted in section 4, at least some of the apparent variation in local authority reported provision being due to data artefacts.

5.42 That said, it is clear from the research that there were many short comings in local authorities' data collection and recording systems, particularly, but not exclusively relating to equality information. Some local authorities were unable to provide information on, for example, the gender breakdown of short break recipients, the number of ethnic minority clients or carers or the volume of short breaks delivered to specific client groups. In some cases, it was acknowledged that this information *could* be made available, but that this would require, for example, a manual count of records.

5.43 In these circumstances, it is not clear how local authorities would be able to demonstrate that they are meeting their obligations in relation to equality.

5.44 There was a widespread recognition that a reliance on volume measures alone would be inadequate once assessments, and flowing from this, provision, were driven by a focus on personal outcomes for clients and carers. There was also frustration evident among some interviewees that at least some of the non-traditional and innovative provision they had introduced was hard to measure using traditional volume-based methods.

5.45 Some local authorities had adopted the Community Care Outcome Framework measures relating to clients' safety and carers' ability to remain caring, with these, in some cases, being embedded in SOAs. There was some concern expressed that, even if these could be adequately measured through, for example, feedback obtained or general client and carers' surveys, they were too general to adequately describe the success or otherwise of a range of provision.

5.46 Some interviewees expressed concern that too close a focus on the achievement of these measures might stifle, rather than promote innovation. The example given was that a significant investment in telecare could lead to a rise in clients feeling "safe", but at the expense of feeling isolated, unfulfilled, and potentially unhealthy.

5.47 Overall, it was clear that personalisation and a focus on outcomes was at a relatively early stage. Later, it will be suggested that some work could be undertaken at a national level to help put in place guidance and support the development, identification and measurement of outcomes.

## *Prevention*

5.48 There is no doubt that prevention, both of carer breakdown and admission to long term care, was seen to have assumed a higher level of significance in recent years. It was also noted by some interviewees that this seems likely to increase as resources are constrained. In effect, admission to long term care (or admission to hospital as in-patient) is expensive and prevention is regarded as, in effect, investing to save. The same argument was also advanced in relation to the avoidance of emergency and crisis situations. Generally, dealing with a crisis would involve either residential care or full-time in-home care, both of which are very expensive.

5.49 It is worth noting that some local authorities had given detailed consideration to what works best in relation to preventing carer breakdown and admission to long term care alongside a more general focus on personalisation. The consistent conclusion appeared to be that support which is flexible, needs-based and produces positive outcomes works best.

## **Short Breaks Bureaux**

5.50 A number of examples of Short Breaks Bureaux (or similar) were identified, and it was clear that a number of local authorities were considering these, or the linked brokerage models. A small number of local authorities had established centralised specialised resources stopping short of a Short Breaks Bureau.

5.51 A wide range of benefits were identified for Short Breaks Bureaux-type arrangements, including: the centralisation of specialist knowledge about forms of provision; it being easier to monitor quality and, at a practical level, in terms of the time saved by removing the advice and booking responsibilities from front line staff.

5.52 The key concern expressed by other local authorities related to the potential cost in terms of staff time and overheads, and the lack of a clear cost-benefit framework against which to judge their potential effectiveness.

## **Self Directed Support**

5.53 The research found very low levels of the use of SDS by clients to purchase short breaks, both among long-standing clients and those who switched to SDS following local authority tendering exercises. A range of barriers were also identified in relation to accessing support.

5.54 A key area of concern for some interviewees was how SDS clients could be better supported both currently and in the future, assuming that SDS becomes the default management option as was proposed in the recent Scottish Government consultation.

5.55 A number of small scale pilot projects were identified through which local authorities were seeking to bring the benefits of SDS without the management burden, or requiring changes to other aspects of the management of care. These pilots were generally at an early stage, and definitive findings on their effectiveness were not available. The potential benefits of these “halfway house” schemes are clear in principle, offering flexibility, but with less administrative burden, and offering

different means of funding short breaks and mainstream care, but it will be important to assess how they work in practice.

### ***Overall patterns of demand***

5.56 Overall, local authorities largely believed that they were satisfying the expressed demand for short breaks, although it was not clear to what extent demand was being depressed by the imposition more stringent eligibility criteria. In this context, it is worth reiterating that most local authorities acknowledged that there was also likely to be some level of unmet need which has never been identified or assessed.

5.57 In some local authorities there was evidence of variation in the extent to which different client groups were able to access their first choice of break, either in terms of timing or location. There appeared, however, to be relatively few waiting lists, except for more specialised forms of provision.

### *Transitions*

5.58 It was clear that the transition between children's and adult services creates difficulties for both young people and families, and presents service providers with difficult choices. None of the local authorities which participated in this research considered that the issue had been addressed fully effectively, although there was considerable evidence of local initiatives designed to, for example, manage expectations and dovetail services. It is likely that there will be good practice examples in such work although, at present, there was found to be no obvious means of capturing these.

5.59 There were a number of examples provided of difficulties in transitions between adult and older people's services, largely as a result of funding or eligibility issues. Some local authorities however, believed that they did not face these issues as their structure was integrated or because specific flexibility had been developed. It is worth noting that some local authorities still appeared to use aged 65 as a break point, even though this no longer realistically reflects the entry point to old age.

### *Rural issues*

5.60 A number of issues were identified with provision in rural areas, largely related to distance and limited availability of specialist provision. It was also clear that difficulties could arise in relation to staff sickness and holiday cover. In some more remote or island areas, it was clear that short break choices may be limited. In these cases, local authorities clearly faced a dilemma in seeking to meet the needs of the client at reasonable cost when the only provision may be on the mainland.

### *Provision to specific groups*

5.61 Arguably the key finding of the report was that there was evidence of considerable variation in the level and nature of provision available to different client groups across Scotland<sup>24</sup>.

5.62 A range of groups were found to face barriers to accessing short breaks, at least in some areas. Issues were identified for all of the different client groups, with particular barriers highlighted within these groups for younger adults with sensory and physical impairments; people with dementia, and particularly those with early onset dementia; some groups of adults with learning difficulties; and particularly adults experiencing mental health problems. People with difficult or challenging behaviour were seen to face barriers regardless of their client group. People with complex nursing care needs also could face barriers in some areas due to a lack of specialist facilities.

5.63 Within client groups, there was also evidence of wide variation in, for example, the types of short break offered, whether some types of short break would not be supported, whether local authorities were prepared to purchase options out of their area and in the limits set in terms of weeks or overall cost.

5.64 For some client groups in some areas, issues were identified about their facing little option but to accept a short break in a facility unsuitable for their age or health-related circumstances.

5.65 There were also, however, a wide range of good practice examples, including the development of custom facilities with examples for most client groups. The development of specialisations within existing facilities (for example, nursing or dementia skills in care homes) was also highlighted, as was the identification and implementation of independent holiday options, often with care being provided by an agency in the holiday area.

5.66 The use of telecare was identified in a number of areas, both as a holding measure until an assessment could be carried out, and as part of a wider care package which may include short breaks.

### *Ethnic minority clients and carers*

5.67 Ethnic minority clients and carers were found to face a variety of difficulties in accessing short breaks, and there was some evidence of local authorities having given little specific consideration to the needs of this group, there was also some evidence of specific services being developed in cities. There was also evidence of a willingness among some local authorities to purchase short break services from providers in other areas.

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<sup>24</sup> It is worth reiterating that this research did not constitute an audit, and that these findings are based on the reported views of local authorities, NHS boards and a range of external stakeholders.

## **SECTION 6: SUGGESTIONS FOR FURTHER ACTION**

6.1 On the basis of the findings set out in Section 5, a number of suggestions for further action are set out below<sup>25</sup>.

### ***Good practice guidance on the development of a strategic context for short breaks***

6.2 The National Guidance recommends the development either of a free-standing short breaks strategy, or at least of a cross-cutting summary strategy or position statement. There is clear evidence that many areas have chosen not to do this, and, as a result, short breaks policy remains spread across a number of service delivery areas. It is suggested that:

- The Scottish Government and CoSLA should consider re-promoting the national guidance with a view to increasing the take up of at least the option of the development of a position statement about short breaks in each area.
- A number of suggestions are set out below in relation to definitions and measurement, and these could be included in the guidance.

### ***Developing a more consistent pattern of provision***

6.3 Given current Government policy, it is the responsibility of each local authority to develop provision to meet identified local needs. Some level of variation is, therefore inevitable, and may reflect different patterns of need. However, it was clear from this research (and from the Scottish Government's own statistical returns) that this could not explain all of the variations evident in short break provision in different areas, and to different client groups. Accordingly, it is suggested that:

- The Scottish Government and CoSLA should review whether the current national guidance is adequate in ensuring that carers and cared for persons have broadly equal access to services regardless of their home location.
- Allied to this, it is suggested that CoSLA's annual guidance on charging should encourage greater consistency between councils.

### ***Eligibility and prioritisation criteria for access to short breaks***

6.4 It was clear from the research that individual local authorities are using different criteria in assessment and particularly prioritisation processes. It was also clear that local authorities are likely to manipulate prioritisation criteria as a way of managing scarce resources. Accordingly, it is suggested that:

- The Scottish Government should consider periodic monitoring of the nature, application and consistency of the criteria used by individual authorities for deciding whether or not to offer a short break to a service user.

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<sup>25</sup> It is also recognised that the implementation of the key action points in the National Carers' Strategy will be important in developing work in the future.



### ***Cost-benefit analyses***

6.5 One of the issues arising from the research was that staff working to develop policy often lack detailed research on the costs and benefits of aspects of short breaks. This issue will become increasingly important as funding pressures intensify. It is suggested, therefore, that two linked pieces of work should be considered to develop cost benefit analyses:

- A general piece of work to consider the costs and benefits of short breaks and benchmark these against other forms of social care
- A specific piece of work to consider the costs and benefits of Short Breaks Bureau-type arrangements in delivering both outcome-focussed and personalised provision

### ***Guidance on identifying unmet need***

6.6 There was a common view among interviewees of all kinds that approaches to measuring or identifying unmet need were limited. It is suggested, therefore, that:

- Shared Care Scotland should convene a small group to bring together non-statutory good practice guidance on ways to identify unmet need (viewed from the perspectives of both carers and cared for persons), and beyond this, on means of engaging with hidden carers. In this context, it would make sense for the NHS to be represented on this group, given the focus on these issues within Carer Information Strategies, as well as the Scottish Government's Joint Improvement Team.

### ***Eligibility and prioritisation criteria for access to services by carers***

6.7 If the Scottish Government decides to extend eligibility for community care services to carers in their own right, it is suggested that:

- Consideration should be given to providing guidance on how eligibility and prioritisation criteria should be developed in order to avoid the potential issue that many carers who are assessed as requiring a service may not be able to access this as they do not achieve a high enough prioritisation when judged against other categories of service user.

### ***Equality Impact Assessments***

6.8 The research found that there appeared to be little awareness of the need for, or benefits of using Equality Impact Assessments. This need for robust equality impact assessment is likely to be heightened as a result of budgetary pressures and the need for prior scrutiny of any cuts to support of services. Accordingly, two suggestions are made:

- A short guidance note is prepared specifically on the use of EQIAs in relation to short breaks and associated support services.
- Local authorities should be asked to report on the carrying out of EQIAs in relation to short breaks (with any consequent actions

arising from these) as part of Scottish Government's monitoring processes.

### ***Carers' assessments and review processes***

6.9 The research found that much work was being done to improve the effectiveness of carers' assessments and review processes. Five suggestions, three of which are linked, are set out below in relation to carers' assessments. The first three relate to sharing good practice:

- A short life working group could be convened to consider the range of outcome and review tools available to local authorities (such as the commonly used method Talking Points) and develop guidance on how to use these effectively, for example, in relation to user training, the choice of specific criteria to be used and the frequency of reviews.
- Good practice examples from local authorities should be gathered and published as a means of highlighting innovation and helping develop consistent practice across Scotland.
- National carers' organisations should gather and publish good practice examples arising from local carers' organisations being able to undertake assessments. As part of this, it is suggested that some guidance should be included on how to ensure that these third party assessments can be fully incorporated into local authority decision making and management processes and, more directly, be afforded the same weight as if they had been undertaken by a care manager.

6.10 Two further suggestions are made in relation to assessments and review processes:

- A small piece of research could be commissioned to investigate the extent to which carers are satisfied with the assessment process, and the extent to which a positive assessment leads to the delivery of a service (whether by a local authority or voluntary organisation).
- As part of the annual returns process, local authorities should be asked to provide data on the number of carers offered assessments, and the number of carers choosing to take up the opportunity.

### ***Measurement and outcomes***

6.11 Although there is a clear movement towards the use of outcome measures, volume measures remain important both for planning and accountability. The research, however, identified that there is currently little consistency in the use of definitions and, allied to this, in measurement, although the work of both Audit Scotland and the Scottish Government in relation to the collation of information to support the annual statistical bulletin is acknowledged. It is suggested, therefore, that:

- Work should be undertaken to update common definitions and measurement categories. This could address issues such as the circumstances in which home care or attendance at a day centre

could be considered to be respite (e.g. where the period of service exceeds a time threshold or where it is identified in a care plan), and whether (and if so, how), the impact of telecare could be reflected in national statistics.

- Related to this, work could also be undertaken to develop guidance to local authorities about how to measure and report on short breaks taken by those managing their own care package using Self Direct Support.

6.12 At present, at least some local authorities seem to find it difficult to identify the volume of short breaks delivered by individual groups of service users (e.g. disabled people, people with learning difficulties or members of ethnic minority communities and even, in some cases, gender). This makes it difficult to assess the extent to which the needs of these groups are being met, and also makes it difficult for public bodies to demonstrate that they are meeting their obligations under equality legislation. It is suggested, therefore, that:

- As part of the development of better definitions and measurement categories, the Scottish Government should develop guidance on how best to capture equality information about beneficiaries (and by extension, carers). Particular regard should be paid to people who fall into more than one group.

6.13 The research identified a concern among many within both local authorities and carers' organisations that there remains a high level of reliance on "traditional" short break options. At present, the national statistical bulletin simply aggregates all forms of overnight break. As part of any work to develop a common set of definitions and measurement categories, it is suggested that:

- The Scottish Government should consider whether future data gathered could better disaggregate different forms of provision.

6.14 One of the most consistent concerns expressed by local authorities was about the development of meaningful outcomes, and ways of both assessing and measuring these. At present, development work appears piecemeal and patchy. It is suggested, therefore that:

- Work could be undertaken at a national level, but involving local authorities, the Scottish Government and others, to help develop a standardised approach to the identification and use of outcomes, as well as guidance on appropriate forms of measurement. Clearly this would impact on national, as well as local reporting arrangements. The work currently being facilitate by Shared Care Scotland in relation to a common evaluation framework could both inform and be informed by this work.

### ***Dual benefit***

6.15 The research found that short breaks work was generally located within the context of carers' strategies as is the case at a national level. However, there are two groups involved the care relationship, and their interests do not necessarily coincide. The national guidance is clear on the need for dual or joint benefit for the cared-for person and carer, and it is suggested that there may be value in exploring ways in which this can be fully embedded in both local engagement and national policy. As a first step, it is suggested that:

- Shared Care Scotland could convene a short life working group of, for example, national carers' organisations, Independent Living in Scotland, Age Scotland and the Long Term Conditions Alliance to produce guidance both on how to ensure that local strategies and policies reflect issues for carers *and* service users, and to advise on the development of outcomes which would be effective for both groups.
- As part of this, it could be helpful for such a group to develop a practice guidance note for assessors to help them deal with situations where the views of carers and the cared for persons are at odds.

### ***Publicising non-traditional options***

6.16 In relation to assisting care managers in becoming more familiar with the range of short break options open to their clients in the context of developing more personalised provision (particularly where this is no Short Breaks Bureau or similar), it is suggested that:

- Shared Care Scotland could (with the assistance of, for example, ADSW) develop a practice guidance note for social work staff focusing on up to date thinking on short break options.
- It is also suggested that local authorities should be encouraged to build on work done by Shared Care Scotland and individual social work departments to build awareness raising about short break options into continuing professional development programmes.
- Local authorities should be encouraged to contribute to, and make use of the new online directory of short break opportunities developed by Shared Care Scotland. At a local level, promotion of the directory to individual social workers should be undertaken as a way of encouraging consideration of less traditional short breaks options.

### ***Self Directed Support***

6.17 Given that SDS support services vary in their capacity as well as their knowledge of short breaks there would be merit in local authorities and Self Directed Support Scotland considering how best to support people using SDS to purchase short breaks, given the likely increase in its use in the next few years. It is suggested, therefore, that

- Self Directed Support Scotland and the local authority SDS network should jointly produce a good practice guidance note for both voluntary and public sector support services on short breaks. Such a note could then be used to benchmark and, if necessary, develop services to people using SDS to fund short breaks.

6.18 The research identified a small number of funding pilots underway which bridge the gap between direct funding and direct payments. It is suggested that:

- Shared Care Scotland could bring together an action learning set as a means of both sharing information and encouraging peer review.

### ***The interface between organisations with shared interests***

6.19 The research identified that there are only limited contacts between, for example, carers' organisations and organisations of and for disabled people, older people or ethnic minority communities, even though all are potentially involved in issues relevant to short breaks. As a means of helping facilitate these contacts, it is suggested that:

- Shared Care Scotland, as part of its programme of conferences and workshops, should consider an event bringing together organisations from each of the interest groups with a view to identifying areas of common interest, and potentially, a sustainable forum through which mutually relevant issues could continue to be discussed.

### ***Transitions***

6.20 The research identified that most local authorities have been working to improve the transition between young people's and adult services. Accordingly, it is suggested that:

- A short life multi-agency working group, involving carer and client groups, as well as both local authorities and health services, could be convened to review emerging practice and ideally develop good practice guidance in managing this transition.

### ***Ethnic minority clients and carers***

6.21 Work is currently being undertaken by MECOPP in relation to ethnic minority clients and carers, and it is suggested that:

- Consideration should be given to how to address issues relating to short breaks for this group, for example, through the development of guidance, staff development resources or through encouraging the use of the Equality Impact Assessment process.

## **Overview**

6.22 It is suggested that all of these suggestions, as well as detailed consideration of the best ways of addressing the wide range of issues raised in this report, will help to enhance and develop short breaks planning and provision in Scotland.

## **ANNEX 1 : TYPES OF SHORT BREAK**

The following are types of short break identified by Shared Care Scotland

### **Breaks in specialist respite accommodation**

This might include specialist guest houses, community flats, purpose-built or adapted accommodation. Depending on the care group catered for, facilities may be able to offer specialist care. This is different to the residential or nursing home option which focuses more on long-term care but might offer some day care and short term respite places.

### **Breaks in residential care homes (with or without nursing care)**

Some homes may have a small number of places set aside specifically for respite breaks. Rather than simply offering a 'spare bed' the home should provide separate facilities with a carefully planned programme of activities for short-term guests to suit individual needs and interests.

### **Breaks in the home of another individual or family**

These involve overnight breaks provided by volunteers in their own home. These are sometimes referred to as shared care, family-based or adult placement schemes. Families or individuals offering this support are carefully recruited and registered - normally by the local authority or through voluntary sector organisations.

### **Breaks provided at home through a care attendant or sitting service**

This includes individual support provided in the home of the cared-for person for periods of a few hours or overnight. The purpose may be to provide cover while the carer is away, or to support the carer in other ways, e.g. by enabling the carer to have an undisturbed night's sleep.

### **Supported access to clubs, interest or activity groups**

These opportunities might focus on a particular activity (e.g. lunch clubs, leisure activities) and may be based in a day centre or community building. These generally take place over a few hours, perhaps once or twice a week.

### **Holiday breaks**

These include opportunities for the carer and cared-for person to have a short break. These breaks can be supported in different ways - through an agency specialising in breaks for people with particular needs, in adapted accommodation or in ordinary hotels and guest houses, perhaps with additional equipment. More mainstream breaks may also be possible with the support of a paid carer or companion accompanying the group.

## **Befriending schemes where volunteers provide short breaks**

Befriending normally involves a paid worker or volunteer accompanying the 'befriender' to social and leisure activities, for example going to the cinema, meeting friends, shopping, swimming and other such activities.

## **Day care**

This is typically based in a community building and provided by a local authority or voluntary organisation. The degree of flexibility varies: most are characterised by fixed opening hours on particular days; some offer a drop in service whereby people can attend for part of the day only. Day care is not generally provided for short break or respite purposes but services which offer more flexible arrangements, designed around the needs of both the client and carer, can achieve this purpose.

## **Hospital-based respite**

The main emphasis will be on those people assessed as requiring medical supervision because of complex or intense health care needs. In these situations it may be deemed beneficial to provide some short term hospital based care which, although not the main purpose, might also bring the added benefit of a respite break for the carer.



## **ANNEX 2 : ACTION POINTS FROM THE NATIONAL CARERS STRATEGY**

The following are the relevant action points from Respite (Short Breaks) chapter of the National Carers' Strategy.

### **ACTION 13.1**

The Scottish Government, in allocating £1m to the national carer organisations in 2010-11 for short breaks provision, will monitor progress towards the provision of innovative, personalised, flexible provision which meets the needs of carers.

### **ACTION POINT 13.2**

In 2010-11 the Scottish Government will work with Shared Care Scotland and others to disseminate the findings of the short breaks research and to consider the development of further actions in light of the findings. In particular, Shared Care Scotland seeks to use the research findings to support partners to improve the local strategic planning and commissioning of short break provision.

### **ACTION POINT 13.3**

For the duration of this strategy, the Scottish Government will undertake to strengthen the NHS role as a strategic partner in supporting the provision of respite care. The Scottish Government will facilitate a high level meeting with NHS Boards to consider current practice, with a view to identifying factors which would help promote/support joint working in this area.

### **ACTION POINT 13.4**

For the duration of this strategy, the Scottish Government with Shared Care Scotland and other partners will encourage and support the continued development of more effective ways of providing short breaks through learning networks and, where possible, the setting up of demonstration projects.

### **ACTION POINT 13.5**

From 2011, the Scottish Government will work with a range of organisations to explore the potential to develop short breaks provision through volunteers.

### **ACTION 13.6**

For the duration of this strategy, the Scottish Government will work with a range of organisations to explore the potential to develop emergency respite and to support carers with emergency planning.

#### ACTION POINT 13.7

The Scottish Government will continue to publish beyond 2011 official statistics on respite provision and will work to improve the quality and consistency of this information, in order to achieve National Statistics status for this data source and publication.

#### ACTION POINT 13.8

By July 2012, the Scottish Government will reassess the timescale for delivery of the Manifesto commitment to a guaranteed annual entitlement to breaks from caring for those in greatest need, taking account of progress in the delivery of short breaks through the other Action Points in this chapter.

## **ANNEX 3 : SCOTTISH GOVERNMENT STATISTICS**

Note: This research focused on adults, therefore, data relating to children has been excluded from this annex.

This data is intended to be indicative of the overall picture as presented in the Scottish Government statistical bulletin “Respite Care, Scotland, 2010”. As set out in the main report, the bulletin contains a large number of caveats and explanatory notes. It is strongly recommended that these tables should be used only in conjunction with “Respite Care, Scotland 2010”.

**Table A1: Total respite weeks for 65 and over**

<b>Area</b>	<b>Population</b>	<b>Weeks</b>	<b>Weeks per 100.000</b>
Aberdeen City	32193	1,880	5,840
Aberdeenshire	39194	3,640	9,287
Angus	21950	3,150	14,351
Argyll & Bute	19054	2,150	11,284
Clackmannanshire	7874	1,760	22,352
Dumfries & Galloway	32391	850	2,624
Dundee City	25598	2,320	9,063
East Ayrshire	20770	2,530	12,181
East Dunbartonshire	19424	5,940	30,581
East Lothian	17267	710	4,112
East Renfrewshire	15886	3,060	19,262
Edinburgh, City of	68964	9,710	14,080
Eilean Siar	5616	980	17,450
Falkirk	24644	1,670	6,776
Fife	62958	8,530	13,549
Glasgow City	81544	8,970	11,000
Highland	40874	3,100	7,584
Inverclyde	14364	9,570	66,625
Midlothian	13266	1,070	8,066
Moray	16258	930	5,720
North Ayrshire	24864	3,210	12,910
North Lanarkshire	49093	5,600	11,407
Orkney Islands	3890	700	17,995
Perth & Kinross	28499	4,910	17,229
Renfrewshire	28206	1,230	4,361
Scottish Borders	22512	820	3,643
Shetland Islands	3720	1,080	29,032
South Ayrshire	23466	1,570	6,696
South Lanarkshire	51490	8,620	16,741
Stirling	15180	750	4,941
West Dunbartonshire	14778	3,820	25,849
West Lothian	22745	840	3,693

**Table A2: Total respite weeks for 18 - 64**

<b>Area</b>	<b>Population</b>	<b>Weeks</b>	<b>Weeks per 100.000</b>
Aberdeen City	143,584	1,020	710
Aberdeenshire	151,496	1,950	1,287
Angus	65,886	370	562
Argyll & Bute	54,087	1,590	2,940
Clackmannanshire	31,735	1,260	3,970
Dumfries & Galloway	87,561	350	400
Dundee City	90,537	3,980	4,396
East Ayrshire	74,822	3,660	4,892
East Dunbartonshire	63,412	1,060	1,672
East Lothian	58,073	410	706
East Renfrewshire	53,058	820	1,545
Edinburgh, City of	327,335	9,190	2,808
Eilean Siar	15,402	170	1,104
Falkirk	95,758	790	825
Fife	226,490	10,750	4,746
Glasgow City	396,527	10,410	2,625
Highland	134,986	1,470	1,089
Inverclyde	49,812	2,990	6,003
Midlothian	49,908	1,980	3,967
Moray	53,398	710	1,330
North Ayrshire	82,536	1,110	1,345
North Lanarkshire	205,451	5,110	2,487
Orkney Islands	12,085	740	6,123
Perth & Kinross	88,818	1,060	1,193
Renfrewshire	107,012	1,880	1,757
Scottish Borders	67,385	670	994
Shetland Islands	13,597	310	2,280
South Ayrshire	66,994	560	836
South Lanarkshire	194,503	2,540	1,306
Stirling	54,860	220	401
West Dunbartonshire	57,414	3,250	5,661
West Lothian	108,819	1,390	1,277

**Table A3: Total respite weeks for over 18s**

<b>Area</b>	<b>Population</b>	<b>Weeks</b>	<b>Weeks per 100.000</b>
Aberdeen City	175,777	2,900	1650
Aberdeenshire	190,690	5,590	2931
Angus	87,836	3,520	4007
Argyll & Bute	73,141	3,740	5113
Clackmannanshire	39,609	3,020	7625
Dumfries & Galloway	119,952	1,200	1000
Dundee City	116,135	6,300	5425
East Ayrshire	95,592	6,190	6475
East Dunbartonshire	82,836	7,000	8450
East Lothian	75,340	1,120	1487
East Renfrewshire	68,944	3,880	5628
Edinburgh, City of	396,299	18,900	4769
Eilean Siar	21,018	1,150	5472
Falkirk	120,402	2,460	2043
Fife	289,448	19,280	6661
Glasgow City	478,071	19,380	4054
Highland	175,860	4,570	2599
Inverclyde	64,176	12,560	19571
Midlothian	63,174	3,050	4828
Moray	69,656	1,640	2354
North Ayrshire	107,400	4,320	4022
North Lanarkshire	254,544	10,710	4208
Orkney Islands	15,975	1,440	9014
Perth & Kinross	117,317	5,970	5089
Renfrewshire	135,218	3,110	2300
Scottish Borders	89,897	1,490	1657
Shetland Islands	17,317	1,390	8027
South Ayrshire	90,440	2,130	2355
South Lanarkshire	245,993	11,160	4537
Stirling	70,040	970	1385
West Dunbartonshire	72,192	7,070	9793
West Lothian	131,564	2,230	1695

**'It's about time: An overview of short break  
(respite care) planning and provision in Scotland**

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BREAKS, FAMILIES  
WILL COPE AND WILL  
CONTINUE TO CARE

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VERY EFFICIENT AND  
MUCH VALUED SERVICE.  
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