



Summary Notes from Sharing Practice Network Event

South Lanarkshire Council, 23rd May 2007

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Summary of Discussion about Draft Respite Guidance

General comments

It is vital that the Guidance provides direction and clarity particularly in relation to the definition of respite and the minimum standards expected by way of service planning/commissioning and provision. In the past the lack of clarity around definitions has led to poorly focused resource allocation and some confusion over what services can and cannot be counted as respite for audit purposes.

How will we know the Guidance is working?

The Guidance, as it stands, does not provide clear outcomes/expectations/improvement targets that could be used for monitoring and evaluation purposes. In the absence of clear outcomes it will be very difficult to establish what impact the guidance is having on the development and improvement of services. It was explained that the Task Group is looking at opportunities to build respite into the development of National Outcomes for Community Health and Social Care services (currently underway) but there was scope to be more explicit about the changes the Guidance is looking to achieve.

Is it appropriate to use the term 'respite' in situations where there is no carer? Is 'respite' the correct definition to use when describing breaks for people in this situation?

There was concern that by including within the Guidance respite for people without carers this may create significant demand on services/resources which were intended to be of primary benefit to carers. On the other hand, the view was expressed that many people who self care (perhaps with some support) benefit greatly from the occasional break from the normal routine. This would apply, for example, to people experiencing or recovering from mental health problems who use respite support a temporary 'release' from the demands of their home environment. On balance it was decided that the Guidance should be inclusive but that it should clarify the purpose of respite in situations where no carer is present. Funding to support respite services in these circumstances may have to be found from other budgets but this would be locally determined.

Can Day Care services be viewed as Respite?

The question was raised as to whether Day Care could/should be regarded as respite. The point in this case being that Day Care budgets are separate from short break/respice budgets but by recognising Day Care as respite, and merging budgets, this would generate a greater resource from which a much wider variety of respite opportunities could be developed. There was concern expressed about counting Day Care as respite as this, in many cases, might not be the primary purpose and therefore may distort the picture of respite provision. For many carers, Day Care is regarded as a basic minimum entitlement which allows some time to catch up with work, education or domestic responsibilities – rather than to provide a break in the true sense of the word.

Where should the responsibility for developing respite strategies lie?

The Guidance provides health partnerships and local authorities with some options with regard to how respite strategies should be produced and where they should be published. These range from a centrally coordinated strategy covering all care groups and ages to care group specific plans. These could be published separately or brought together in one document, perhaps the Carers Strategy. There was a view that a centrally coordinated document would provide the necessary status and focus and encourage a more joined up approach to service development. It was suggested that the Guidance should strongly encourage this approach, if not specify.

Respite Guidance Discussion: Flip Chart Comments

- Which forms of Day Care will fall within the definition of short breaks and respite within the Guidance?
- Does the Guidance in relation to Day Care, Befriending, Adult Placement have these respite options as defined within the Regulation of Care (Scotland) Act 2001?
- Monitoring and Evaluation – there needs to be very clear definitions to explicitly capture the correct activity/outcomes to make comparison between LA's/Health Boards.
- What links does the Respite Task Group have to the ongoing work on National Outcomes?
- What links with Children and Families Service Planning?
- As far as the list of examples of respite/short break activities is concerned, need to add Clubs, Interest or Activity Groups where these are not part of traditional day care. For parents/carers of children in particular this is an important and valuable form gaining a break.

Top 5 Topics for future Sharing Practice Network Events

- Invite to Health colleagues to discuss partnership working in relation to respite planning and provision
- How do we establish clear eligibility criteria for access to respite and short break services?
- What are the main obstacles to accessing respite services and how can these be minimised or eliminated?
- How can we be more 'innovative' about how we use funding to pay for respite and what options are available?
- What can we learn from other parts of the UK in the area of short break and respite provision?
- How can we involve carers and service users in the development of respite strategies?

South Lanarkshire Council HQ
 Conference Rooms 1 & 2
 Almada Street
 Hamilton



Wednesday 23rd May 2007

SHARING PRACTICE NETWORK: PROGRAMME

- 9.45am **Registration & Coffee**
- 10.15am **Welcome & Introductions**
- *Mary Yates, Manager, Share Services, South Lanarkshire Council*
 - *Don Williamson, Chief Executive, Shared Care Scotland*
- 10.30am **Scene Setting:**
- Delivering Good Practice:** Key messages within the Respite Guidance
- *Peter Stapleton, Head of Carers Policy Branch, Scottish Executive*
- Putting Policy into Practice**
- *Deborah Mackle, Planning and Development Officer, South Lanarkshire Council*
- 11.40am **Visit Briefing**
- *Don Williamson, Shared Care Scotland*
- 12.00pm **Lunch**
- 12.30pm **Depart to Visits** (*tea & coffee served at visits*)
- Seven visits have been arranged to different short break and respite service providers. The services cover a broad range of care groups from children to older people and different forms of support including home care, befriending services, holiday breaks and residential accommodation. Carers and service users will also be present at some of the places visited. The purpose of these visits is to explore the challenges of delivering effective services and turning policy into practice.
- 2.00pm **Return from visits and preparation for Report Back**
- *Group Work*
- 2.30pm **Report Back & Discussion**
- *Harry Stevenson, Executive Director of Social Services, South Lanarkshire Council*
- 3.30pm **Feedback on the day, date, topics and location for next event**
- 4.00pm **Close**

**Respite Guidance – Presentation to Shared Care Scotland
Peter Stapleton, Head of Carers Policy, Scottish Executive
MEETING - 23 MAY 2007**

Background

The decision to update this guidance followed the Executive funded Care 21 Report on *The future of unpaid care in Scotland* – which remains the largest study of its kind in the UK. The report captured views of professionals and unpaid carers, and used economic models to make 22 recommendations for improving carer support over 10 years.

The Executive's response to the report was published last April. It refocuses the *Strategy for Carers in Scotland* (1999) and fits with *Delivering for Health's* emphasis on prevention and self care, echoing similar messages in the social work review *Changing Lives*.

The response set out work on almost all of the 22 recommendations, including work to prepare an evidence base to inform decisions about provision in the spending review. It identified priority actions in four main areas, including respite.

The response accepted the value of a strategic approach to respite and established the Respite Task Group to, amongst other things '*update national strategic guidance for respite services ... to help shift the focus of local provision to preventative, personalised respite care ... [and] to set out what should be covered in local service planning and to underpin Local Improvement Targets for Respite Services.*'

The Task Group has involved representatives from local authorities, the NHS, inspection agencies and voluntary organisations – including Shared Care Scotland.

Principles

The first thing the Task Group did on this was to look at the old 1996 respite guidance and think about what we wanted to achieve with an update.

- We decided that there was a lot of excellent material in the 1996 guidance. Interestingly, we concluded that there would be little need for a review if all that had been said there

had become mainstream practice today. We have therefore made a conscious effort to keep the best aspects of the 1996 guidance.

- We decided to aim for guidance with the widest application - generic across for carers and different groups of service users, whether or not a carer is present.
- We have made a real effort to keep the guidance as concise as possible. There was a strong feeling across the group that a short document covering the main points would be far more likely to actually be used than a 30 page tome. The main body of the current draft is 8 pages and we are trying very hard to keep it at 8 pages.
- Linked to that aim to see the guidance used, we have worked hard to keep the text accessible and readable, not only for practitioners but also for service users and carers.
- In terms of content, and in line with the group's brief, the draft aims to promote personalised, preventative respite. And it emphasises the links to Local Improvement Targets and to service planning.

Guidance content

In terms of the guidance itself, I thought it would be helpful to run through the main points covered by the draft.

- Definition – based on the care standard for short breaks and respite and showing the variety of services which can constitute respite and short breaks
- Evidence base – Pointing to the research evidence of both the value of respite and its purpose.
- Policy context - How respite sits with wider policy, including *Changing Lives, Delivering for Health* and *Getting it Right for Every Child*.
- The importance of strategic planning and advice on the rather blurred dividing line between the complementary responsibilities of the NHS and local authorities.
- Some guidance on the types of respite, including ...
 - Personalisation
 - Emergency respite and prevention
 - And self directed care (the new terminology for Direct Payments).
- There is a section on information, including Respite Bureaux and the role of Shared Care Scotland

- There is a rather difficult but very important section to help authorities with decisions about eligibility, access for services and prioritisation.
- There is a section setting out the arrangements for monitoring and regulation.
- And finally, there is a section on charging – which mainly summarises and points to the relevant charging guidance.

Annexes

The Annexes supplement the main guidance by moving it from generic advice to specific issues.

Annex A – Sets out the characteristics of good respite care – most of which are covered in the main text but we felt it valuable for them to be pulled together.

Annex B – Covers different types of respite – giving examples of good practice showing how different types of provision can be made to work well for carers and service users.

Annex C – Covers care groups and groups of carers – linking back to the advice on eligibility and highlighting their particular respite needs and risks to be considered.

Annex D on sources of information will probably be dropped.

What next?

Finally I want to explain what needs to happen to finalise the guidance for publication. There are still some refinements to be made following the Task Group's meeting last week. After that, and legal checking, it will need to be shared with new Ministers. If they agree and subject to any changes, we are hoping to issue for an extended public consultation starting next month.

Building in time to take the results on board, I would estimate we are looking at publication around the turn of the year.

Before I close, I would like to leave you with the purpose of the new guidance, paraphrasing the Care 21 response *to help promote a more strategic approach to respite planning and to shift the balance towards more preventative respite and greater personalisation.*

DRAFT NOT FOR CIRCULATION

SCOTTISH EXECUTIVE COMMUNITY CARE CIRCULAR CCD/???

Local Authority Directors of Social Work
Local Authority Directors of Children Services

Copy to: Local Authority Chief Executives
 Local Authority Directors of Finance
 Local Authority Directors of Education
 Health Board Chief Executives
 Appropriate Voluntary Organisations
 Association of Directors of Social Work
 Association of Directors of Education in Scotland
 Convention of Scottish Local Authorities
 Care Commission

GUIDANCE ON RESPITE CARE

Summary

1. This guidance provides advice to Community Care Partnerships and to agencies engaged in children services on the planning and delivery of respite care. It should also be of interest to other individuals and organisations involved in social care. Respite care is an essential part of the overall support provided to unpaid carers and those with care needs and helps to sustain the caring relationship, promote health and well being and prevent crisis.

2. This guidance replaces *Scottish Office Circular SWSG 10/96*¹. While many aspects of that document remain valid, this new guidance emphasises new policy and evidence on the value of:

- working with carers as partners in the provision of care;
- shifting the balance of care towards preventative support and enabling self care in the community, where respite has an important role to play; and
- personalisation in improving outcomes both for carers and those with care needs.

3. These themes are important aspects of the Executive's overall policy direction for both health and social care services, as set out in *Delivering for Health* (2005) and *Changing Lives* (2006) as well as the *Scottish Executive's Response to 'The Future of Unpaid Care in Scotland'* (2006) – which included the commitment to develop this guidance. Personalisation of services and improving outcomes are also consistent with the Executive's priorities for services for children and young people described in the *Getting it right for every child* programme and in guidance on integrated services planning and quality improvement.

4. Recipients should use this guidance to update their strategic planning of respite services. [Local Community Care Partnerships are already required to set and report on Local Improvement Targets under the Joint Performance and Information Assessment Framework and this document provides guidance on that requirement from 2008/09 onwards, *Note – To be updated with reference to National Outcome Measures and LITs once situation is clearer.*].

Contact Point

5. For further copies or for queries about this circular, please contact

¹ <http://www.scotland.gov.uk/library/swsg/index-f/c161.htm>

OUTLINE DRAFT

SCOTTISH EXECUTIVE COMMUNITY CARE CIRCULAR CCD/?/06

GUIDANCE ON RESPITE CARE

Introduction

Definition¹

6. Respite (sometimes referred to as short breaks) encompasses a wide range of different short term services. The common factor is not what service is provided but its purpose – *to provide a break which is a positive experience for the person with care needs and the carer where there is one.*

Respite can be offered in a wide variety of ways including:

- breaks in respite-only units (specialist guest houses, community flats, purpose-built or adapted houses);
- breaks in care homes;
- breaks in the home of another individual or family who have been specially recruited (such as adult placement schemes);
- providing minor equipment to help facilitate a short break in the home of family or friends;
- breaks at home through a care attendant or sitting service;
- [?seperate bullet on breaks providing activities in the community];
- holiday breaks;
- supported breaks for the person with care needs and their carer together;
- befriending schemes where volunteers provide short breaks;
- peer support groups (e.g. for young carers);
- breaks in supported accommodation; and
- breaks using self-directed support².

7. Also some forms of day care may be seen as falling within the definition of short breaks and respite care. Although a service for the person needing care, befriending is also included to cover breaks providing alternative recreation with a befriending escort, which are sufficiently regular and long enough to also provide a break for the carer.

8. In this guidance, the term ‘respite’ is mainly used but ‘break’ is also included. Unless specifically described in the text, both terms refer to situations where a short break is needed, both where there is a carer looking after someone and where a service user has no carer.

Evidence of value of respite and purpose of respite

9. The principal evidence of the value of respite care is based on the perceptions of carers, discussed in reviews of studies such as *Making a Break*³ and confirmed by the ‘Voices of Carers’

¹ Developed from the National Care Standards for Short Breaks and Respite Care Services for Adults - <http://www.scotland.gov.uk/Resource/Doc/69582/0017383.pdf>

² Self directed support (historically known as direct payments) enable individuals to achieve greater choice and control over how their social care needs are met by directing and/or managing support arrangements themselves. Individuals are able to purchase support from a care provider or agency, a personal assistant (PA) or from a neighbouring local authority. [DN insert link to new guidance due in June]

³ *Making a Break: Developing methods for measuring the impact of respite services* (2004). Chesson RA and Westwood CE Aberdeen: The Robert Gordon University.

survey which formed part of the evidence base of the Care 21 Report *The future of unpaid care in Scotland*⁴. Respite is effective in:

- helping carers to safeguard their health avoiding physical or emotional exhaustion, and enabling them to continue caring;
- preventing social isolation - providing a break from their usual routine for people with care needs and carers, enabling them to take part in leisure or other activities;
- overcoming a crisis, such as the carer not coping, cared for person's health deteriorating, or bereavement;
- making time for carers to spend with family and friends; and
- helping people (particularly those cared for by their parents) develop independence and prepare for the time when the carer cannot continue caring.

10. Respite was found to be most effective in providing a break for carers when they were confident in the arrangements and did not need to worry about the person with care needs. This finding supports the observation that some carers and those they care for can be unwilling to take up some types of respite and reinforces evidence for the value of choice and personalisation in respite provision. In particular, respite is seen as cost-effective in enabling those with care needs and their carers to maintain their health and continue living at home.

Status of guidance

11. This guidance is to assist partnerships to meet their responsibilities to plan and deliver respite care but it is also designed to be accessible to other interested parties including service users, carers and service providers. Respite is a key service to prevent crises and enable carers and those with care needs to continue to live at home, although for young carers, the primary aim should be enabling them to be children first. The Executive is promoting the development of strategic approaches to expand and improve respite services through this guidance [which underpins partnerships' responsibilities to set and report on Local Improvement Targets (LITs) under the Joint Performance and Information Assessment Framework. Through LITs, Local Partnerships are to prioritise respite services and set targets for their expansion. *Note – To be updated with reference to National Outcome Measures and LITs once situation is clearer.*]

Policy Context

12. The importance of supporting carers and enabling people to live independently at home are both well established aspects of the Scottish Executive's approach to health and social care. We recognise the crucial contribution which unpaid carers make to Scottish society and that unpaid care is likely to grow in importance. The *Strategy for Carers in Scotland*⁵ (1999) has been refocused through our major Care 21 Report – *The future of unpaid care in Scotland* and the Executive's Response⁶ (2006). The response focuses on four priority areas, including respite and carer health.

13. These documents, as well as *Delivering for Health*⁷ (2005) and *Changing Lives*⁸ (2006) which set the Executive's overall policy for both health and social care, contain a number of themes which are fundamental to this guidance:

- working with carers as partners in the provision of care;
- joint-working;
- shifting the balance of care towards preventative support and enabling self care; and

⁴ *The future of unpaid care in Scotland* (2005). Report by Care 21 Unit and Office for Public Management for the Scottish Executive. <http://www.scotland.gov.uk/Publications/2006/02/28094157/0>

⁵ <http://www.scotland.gov.uk/library2/doc10/carerstrategy.asp>

⁶ <http://www.scotland.gov.uk/Publications/2006/04/20103316/0>

⁷ <http://www.scotland.gov.uk/Publications/2005/11/02102635/26356>

⁸ <http://www.scotland.gov.uk/Publications/2006/02/02094408/0>

- personalisation of support.

14. Personalisation of services and improving outcomes are also important aspects of the Executive's priorities for services for children and young people described in *Getting it right for every child* and in guidance on integrated services planning and quality improvement.

Strategic Planning

15. Respite has a significant part to play in improving the outcomes for people who use services and their carers. Responsibility for the planning and delivery of care services including respite lies with Community Care Partnerships and with the local partnerships which plan, design and deliver services for children and young people. We understand that despite this being clear in the 1996 respite guidance, there is still considerable variation in the extent to which authorities have planned respite services. Partnerships need to apply the same rigour to respite services as they do for services in the round. So they need to have a clear vision of what they are trying to do and the results they expect from respite; how together they plan to invest in services; and how they will know they have made a difference.

16. Executive guidance on *Integrated children's services planning* includes young carers within a list of examples of children in need. The *Quality Improvement Framework for Integrated Services for Children* also refers to respite care (under the "Nurtured" heading). The *Getting it right for every child* programme builds on this approach by placing the needs of the child at the centre of service delivery, regardless of what these needs might be, and encourages local agencies to work together to meet needs through individualised plans. Local authorities have a duty under the Children (Scotland) Act 1995, to safeguard and promote the interests of children in need, including disabled children and young carers. Also to assess the support needs of children and, where appropriate, their carers, which can include respite.

17. The Arrangements to Look After Children (Scotland) Regulations 1996 applies conditions to short-term placements of children where:

- (a) all the placements occur within a period which does not exceed one year;
- (b) no single placement is for a duration of more than 4 weeks; and
- (c) the total duration of the placements does not exceed 120 days.

18. This requires such placements to be reviewed regularly. National Care Standards will also apply to the provision of such placements. The NHS should work closely with its partners to ensure that the need for short-term (respite) placements is identified for looked after children and others with specific medical, physical and behavioural needs and their carers, including parents, kinship and foster carers.

19. Joint planning needs to recognise not just the intended direction but also any shifts in resourcing between agencies in the way services are provided, and the implications that has for them. Short-term care (respite) previously provided by the NHS for people whose needs are predominately for social care is increasingly being commissioned by local authorities. It is important that partnerships plan such changes together, with the involvement of users and carers. NHS Boards and local authorities should therefore agree their complementary responsibilities for short-term health care respite and social respite care, both planned and emergency. In particular, NHS Boards are responsible for addressing the needs of:

- people assessed as having complex or intense health care needs and who require specialist clinical supervision during a period of short-term care;
- people who require or could benefit from active rehabilitation during a period of short-term health care (respite);

- people who are receiving a package of palliative care in their own homes but who would benefit from having a period of in-patient or day hospital care. In many cases, this will bring the added benefit of respite to the carer.

20. In these cases the health needs of the person receiving respite often (but not always) require it to be provided in a health care setting. NHS Boards should review local guidelines on responsibility for continuing care and/or respite to ensure that it meets these requirements. (See also **paras 19 and 20** below on other NHS responsibilities.)

21. Strategic plans for respite should set out a systematic joint approach for the delivery of both planned and emergency respite, including care/carer assessment, eligibility criteria, staff training and information. They should include, as well as the points in **para. 9** above, measures for monitoring of provision and need, involving those who use the services in reviewing services against agreed standards. Plans should identify responsibilities for delivering measurable short, medium and long term goals and be based on:

- multi-agency development and delivery, involving Local Authorities, NHS, carers and service users, voluntary sector organisations and service providers; and
- clear understanding of the range and volume of existing provision, its strengths, weaknesses and gaps, based on local needs including feedback from service users and carers.

22. It is for local partnerships to decide whether to develop specific respite strategies or to include their strategic planning in wider Carers Strategies, Community Care Plans, Integrated Children Services Plans or plans for specific groups of service-users. The bottom line is that there is a clear vision and delivery package – its precise location is of lesser importance.

Types of Respite

23. As noted above, the evidence shows that personalisation is important in ensuring respite has a positive outcome for both those with care needs and carers. This can be achieved by making sure that those with care needs and carers are aware of their options and by building in as much flexibility as possible to adjust provision to individuals' needs. Annex A sets out the main indicators of good respite. The main types of respite are set out in the definition of respite services above and Annex B provides examples of good practice in providing personalised respite.

24. NHS Boards provide a range of services for patients/users that can also have the benefit of providing respite, despite that not being the primary purpose of those services. These can include day services for people with a learning disability, a mental health problem or a physical disability and day hospitals and assessment services for frail older people and older people with mental health problems. **[Can we add anything about the nature of these services – regularity and duration?]**

25. NHS Boards should review how their services can support respite services that are not provided in an NHS setting by meeting the continuing healthcare needs of the person receiving respite. For example, there is already a well established system for providing renal dialysis for patients on holiday within the UK and there are also many local arrangements where NHS community services support other agencies that provide respite. There are also examples of NHS Boards jointly funding respite services with local authorities in order to ensure that all the needs of the person receiving respite are met.

26. Planned, scheduled respite is an effective way of sustaining caring, helping people to remain in the community. It is most effective if used as an early intervention (preventing crises) is regular and flexible.

27. However, it is important for people to have access to emergency respite, where a carer needs an urgent break. This can be to respond to or prevent a crisis, possibly to protect individuals or carers

who are at risk. For example due to ill health of the carer, a deterioration in the health of the person they are looking after, or to respond to a crisis such as a bereavement. Services will need to be available at short notice, with the duration unknown, but limited.

28. The more traditional model of respite provided in residential care home and day care settings will be appropriate for some but carers and service users benefit from being able to select from a wider variety of alternative options to satisfy different needs and circumstances, which may change over time.

29. The aim should be to provide service users and carers with greater choice and flexibility to determine, how, where and when their services are provided. Inevitably there will be limits to the extent to which every service can be individually tailored, but carers and service users have identified certain factors that are particularly important^{9 10}:

- access to respite and short breaks in different settings;
- the option to have a break with or without the cared for person;
- access to respite at different times of the day/week;
- a choice in the length of break;
- flexibility over when respite is arranged; and
- confidence in the quality of care provided.

30. Increasing the range and flexibility of short break services should therefore be central to local strategic planning, moving away from an over reliance on care home and day care services.

31. Self-directed support provides a valuable option for people to have greater flexibility, choice and control over their respite arrangements. The money provided to meet their assessed needs may be used for a short break in a traditional residential setting or alternative models - for example, to pay for a personal assistant to accompany a user on a holiday break, (with or without the carer), or for children to have a short break with a specialist care worker. This type of model can enable all parties to enjoy a family holiday. (Limits on the length of stay purchased in residential accommodation are set out in national guidance¹¹.)

Information

32. Easy access to information is very important to enable both carers and service users to decide about the respite services and support that would be best for them. Information should cover the full range of services available; how to access services; assessment procedures; charging policies or eligibility criteria that apply and where to go for more detailed guidance and support.

33. The mechanisms for communicating this information should be set out within local strategies for involving and engaging with carers and service users, including Carer Information Strategies¹². In many areas this will include advice from local carer centres. Particular attention should be paid to targeting information to under represented groups such as black and minority ethnic communities. Health and social care professionals will need to be proactively involved in informing carers and service users about their respite options. To do this effectively they will need a good knowledge of the services available and how to access further support.

⁹ *Review of Respite Services and Short Breaks from Caring for People with Dementia and their Carers*, National Co-ordinating Centre for NHS Service Delivery and Organisation, Arksey, H et al (2004)

¹⁰ *Making a Break: Developing methods for measuring the impact of respite services* (2004). Chesson RA and Westwood CE Aberdeen: The Robert Gordon University

¹¹ [Insert link to new Direct Payments Guidance once issued]

¹² http://www.sehd.scot.nhs.uk/mels/HDL.2006_22.pdf

34. More detailed information on respite options should be easily accessible and carers and service users given the opportunity to discuss their particular needs, identifying the outcomes they want and how respite might help achieve them. This could form part of the care/carer assessment and review (but other means of accessing this support and guidance should be available).

35. It is important that carers and services users understand that assessment is the start of an ongoing process, where any service provided is regularly reviewed. This will ensure that the care package, including respite care, continues to deliver the agreed outcomes and responds to the carer and care recipient's changing needs and circumstances.

36. Respite Bureaux offer a valuable "One Stop Shop" approach to providing information and access to a variety of respite breaks. Bureaux aim to make the process of accessing respite as streamlined and user friendly as possible working from information obtained from care/carer assessments. Because respite is their speciality, bureaux are successful in identifying flexible breaks which are tailored to the needs of the individual and their carers.

37. Many national charitable organisations publish information and advice on short break and respite services catering for their particular client groups, and some offer specialist respite facilities or short break opportunities. Shared Care Scotland provides a central source of information on these services along with advice on policy and practice, practitioner networks and learning events. A full list of organisations offering support in this area is provided in Annex D.

Access to Services / Eligibility

38. As noted above, respite is crucial in enabling many carers and service users to protect their health, prevent crises and continue living at home. Decisions about provision will form a central element of local strategic planning for respite. It is clearly good practice for service users and carers to be involved in the development and review of eligibility criteria and for all parties to understand these and the respite options available.

39. Partnerships should therefore publish clear eligibility criteria for both planned and emergency respite services, based on the outcome of assessments, which:

- Are focused on prevention - designed to help individuals remain at home, sustaining caring relationships and preventing crises;
- Provide different criteria where appropriate for different user and carer groups, prioritising those most at risk, such as:
 - carers who themselves suffer from ill health or disabilities;
 - those with the most intensive caring responsibilities, caring for people with long term conditions which are fluctuating or deteriorating;
 - older carers;
 - young carers;
 - co-resident carers;
 - carers of people with unpredictable or challenging behaviour including people who misuse substances and people with mental illness or dementia;
 - those caring for a long time;
 - carers of people with a terminal illness; and
 - carers with multiple caring roles.
- Are designed to enable carers to remain in employment, if they wish to do so.

40. Particular risks and characteristics to be taken into account for many of these groups are explained in more detail at Annex C.

Monitoring, Quality Assurance and Regulation

41. As noted above, effective service planning needs to be informed by a clear understanding of the range and volume of existing provision, its strengths, weaknesses and gaps, based on local needs including feedback from service users and carers. Local partnerships are already required to report to Audit Scotland annually on performance indicators for respite provision for children, adults and older people. Partnerships are also required to set and report on Local Improvement Targets for expanding respite services and focusing them on priority areas. *[Expand on LITs requirements and purpose once situation clearer.]*

42. Where respite is offered in care services defined under the Regulation of Care (Scotland) Act 2001 (e.g. care homes or day care services), these are regulated by the Scottish Commission for the Regulation of Care ('the Care Commission'). The Care Commission regulates these services under the Act (and regulations), taking account of the appropriate National Care Standards (NCS). In addition to service specific NCS, the Standards for Short Breaks and Respite Care¹³ apply to all regulated services where respite is offered. The standards address the service user's needs and the needs of their carer or family (or both). They cover some services that rely on volunteers. The respite standards are designed to achieve a balance in which service quality is guaranteed and a range of models can be developed.

43. Some services to the person for whom the respite service is being primarily provided may incidentally provide the carer with a break. These indirect sources of support are not included in the scope of the respite standards.

Charging

44. Separate charging arrangements apply for respite provision in residential care and other settings, but local authorities have significant discretion on charging for respite care in both cases. Charges are made to adult service users, and should not extend to their families or carers.

45. For the first 8 weeks in a care home, local authorities are not required to carry out a formal assessment of a person's ability to contribute towards the cost. During that period the authority should only charge what it considers reasonable for the resident to pay having regard to his or her resources and financial obligations, particularly in respect of maintaining his or her own home. The basis for making any charge should be clear and made available. After 8 weeks of continuous care authorities must charge the resident at the standard rate for the accommodation and carry out a formal assessment of ability to pay, in line with the regulations. The assessment should still take into account the temporary nature of the stay. The repeal of the liable relatives rule [will mean] that local authorities can no longer ask a spouse to contribute to a person's care home fees¹⁴.

46. Charging for other respite accommodation, such as holiday breaks or other supported accommodation, will vary according to its management and provision.

47. Local authorities have discretionary powers to charge for non-residential care services, excluding those classed as free personal care for those aged 65+. The Executive's general guidance on home care charging was issued in 1997¹⁵ and COSLA issued guidance in 2006 to improve consistency in local charging policy¹⁶. As for residential care, authorities should not charge more than an individual could reasonably afford to pay. The basis for making any charge should be clear and made readily available on agreeing the service.

¹³ <http://www.scotland.gov.uk/Resource/Doc/69582/0017383.pdf>

¹⁴ *[insert link to Liable Relatives repeal guidance when issued]*

¹⁵ <http://www.scotland.gov.uk/library/swsg/index-f/c172.htm>

¹⁶ <http://www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc>

48. When considering charging policies, it is necessary to have regard to the wider longer term effects. In line with the principle of working with carers as partners in the provision of care, cumbersome assessment of ability to pay, and charging policies which discourage the use of effective respite services are not in the best interests of users or carers or of the effective use of local authority resources. Poor uptake of respite which increases the burden on carers can lead to caring relationships breaking down and a subsequent need for more expensive services such as permanent residential care.

**Scottish Executive
Community Care Division
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Indicators of Good Respite Care

Particular indicators of good respite care are that it is:

- based on thorough assessment and on-going review,
- appropriate to the needs and circumstances of the carer,
- appropriate for the age, culture, and level of need of the care recipient,
- able to maintain or improve the well-being of the care recipient,
- delivered by appropriately trained and caring staff, and
- affordable.

Personalised Respite – Examples of good practice

This annex offers guidance on the variety of approaches that can be taken and the different outcomes (although it does not provide a comprehensive list). Respite occurs in a range of contexts and many service users and carers will need access to different types of respite and short-term breaks to meet different purposes and needs, possibly in combination with other community care services. It is important to stress the value of involving the carer and care recipient in determining their goals and outcomes for the short break. Evidence suggests that respite ‘fails’ when carers and care recipients have little control or influence.

Breaks in a care home

Although there is evidence of many people being uncomfortable with taking up a respite place in a care home, some will be happier to try this type of break if they can visit beforehand to see the facilities and meet the staff and make any special arrangements for the individual such as arrangements to host daily visitors during a week’s stay. For some, however, the change of routine and environment may be too much, resulting in anxiety and confusion. Other forms of break may be more suitable.

Flexible booking of care home respite

Giving more control to those needing respite can improve choice and make better use of resources. For example, one local authority has booked a respite bed for people with dementia for the year in an independent care home. Families are allotted a number of nights of respite, up to four weeks, and enabled to book time as they wish with the home manager. People now have more control over their respite arrangements and can negotiate changes directly with the manager, rather than going through busy social workers. In the first year of this arrangement, the respite bed was used every night, a big improvement on previous years.

Community-based activities for adults with a learning disability *[and others?]*

Community-based activities for adults with a learning disability can promote independence while providing an effective alternative to traditional, building-based respite. Successful services offer a variety of regular activities such as sport and leisure activities and educational courses and seek to match staff to clients with similar interests.

Breaks for young carers

[Example(s) to be added.]

Breaks in the home of another individual or family

These breaks are sometimes referred to as ‘Shared Care’, where children and young people are concerned, or ‘Adult Placements’, where clients are adults. The service is essentially the same involving specially recruited and trained individuals who are able to offer breaks in their own home. The ‘homely’ environment is an attractive feature of this form of break, plus the opportunity to build longer term relationships between host families, the carer and the care recipient.

- National Association of Adult Placement Services
- Shared Care Network
- The Fostering Network Scotland

Breaks at home

Regular, weekly short breaks at home are the preferred respite option for many people. ‘In Home’ breaks can be provided through sitter services or by personal assistants taking over caring responsibilities for a short period. The familiar surroundings can reduce feelings of anxiety and confusion and offer opportunities to tailor activities to the individual preferences of the care recipient. Services are particularly effective when they can be flexible, allowing those receiving the service to negotiate with the providing agency to adjust times to suit particular circumstances. Carers and service users also benefit from consistency, allowing them to get to know people over a long period. Befriending services can enable care recipients to leave the home and take part in social and leisure activities, promoting self esteem and confidence. However, breaks at home might not suit the carer where the purpose of the break is to provide them with time at home, free from any caring responsibilities, to rest and recover or spend time with other family members.

- Crossroads Caring Scotland
- Befriending Scotland

Providing Equipment to facilitate respite

Providing minor equipment can be invaluable to help facilitate a short break in the home of family or friends. For example, providing bed blocks, *[check terms]* a raised chair and toilet seat could make an older person with mobility problems much more comfortable about staying with someone if they knew they would be able to get in and out of chairs and bed easily and visit the toilet unaided.

Equally, for carers and cared for people living together, equipment such as an emergency alarm can make it safer for the person to remain at home alone for short periods. This can also be invaluable in enabling the carer to re-join regular activities outwith the home.

Involving service users and carers in respite planning

It is clearly good practice for those likely to use services to be involved in planning. For example, a group of service users, carers, health and social work reviewed what respite would be needed to respond to the closure of a particular NHS respite facility. In this case, more short holiday break respite was identified as the priority. A local provider of residential respite was keen to develop this service in the form of a caravan at a nearby holiday park. Because this was what carers and service users wanted, the facility has proved popular and is well used.

Respite in Supported housing

Residential respite in a single tenancy can provide a successful respite model where people, often with very complex physical needs, can be supported by individualised support staff to enjoy community facilities or just a rest.

Day care

Day-care covers planned services provided outside the home of the care recipient, not involving overnight stays. The extent to which traditional day-care services provide ‘personalised respite breaks’ has been the subject of much discussion. Many carers view day-care as a basic entitlement and that short breaks and respite services should be provided over and above this level of provision. However, there is no reason why day-care shouldn’t be considered as respite when the service is carefully designed to deliver this outcome, and meets the agreed needs of both the carer and care recipient. The duration, timing and accessibility of the service are important factors in this regard, alongside the opportunity for activities which provide for personal and social development.

Self-directed support for respite

Self-directed support (through direct payments) is a proven way for people to have a range of respite and short break experiences both within their own homes and at holiday destinations of their choice (see Holiday breaks).

Holiday breaks

The holiday break gives access to mainstream holiday provision through the availability of additional support, specialist providers or access to adapted holiday accommodation. Holiday breaks can provide social stimulation, new activities and being with different company in new environments.

The carer and cared for person can take a holiday break together or apart, depending on the purpose of the break. Breaks together offer an opportunity to escape the daily routine and to enjoy 'normal' experiences together, perhaps as a family. A personal assistant or companion might accompany them to provide additional support and to relieve the carer of some of the caring responsibilities.

- Shared Care Scotland

[Similar examples?]

Respite needs of specific groups

[Short para needed on groups of carers service users where it is valuable to provide guidance to local partnerships, covering particular risks or needs for a break, appropriate types of respite and sources of information. Groups should include:

- older carers,
- young carers,
- people with mental health problems and their carers,
- co-resident carers,
- people with learning disabilities and their carers,
- carers/service users from black and minority ethnic communities
- people with autism spectrum disorders,
- people with profound and multiple disabilities,
- etc.]

Young carers

[Para to be added.]

Those caring for a long time

Carers in a long term caring situation are often at risk due to the cumulative effects of long term caring on carers' health and wellbeing and may become isolated.

Adults living with older parent carers

For adults (e.g. with a learning disability) living with older parent carers, respite can be especially valuable in helping both parties to plan and prepare for the time when the carer will not be able to continue providing the same level of care.

Carers of disabled children

Caring for a disabled child, 24 hours a day can be very challenging for the child's family – physically, emotionally and often financially. Short breaks and building families' capacity to care can have positive benefits for both children and carers, helping to alleviate carer stress.

Carers of people with a terminal illness

In the case of palliative care, carers may require more regular breaks as they are also coping with the grieving process. There may also be a need for more specialised services.

Carers suffering stress

Consideration should be given to prioritising respite to allow carers to access services which will enhance their coping mechanisms and help them to develop support networks. For example, regular attendance at a carers support group, counselling or a carer training course.

Caring relationships under pressure

Respite can be particularly valuable where the caring situation is in danger of breaking down due to stress on family relationships caused by caring responsibilities. (Often counselling and additional support is needed to allow people to come to terms with changing relationships.)

Carers with multiple caring roles

Such situations are often stressful and there is often the tendency to look at each caring situation in isolation, without taking account of the cumulative effect.

[*Further examples?*]

Sources of respite information

[Possibly combine with Annex D.]

The Family Fund makes small grants to families on low income with severely disabled children. Grants can help families pay for a range of essentials, including holidays that are not generally provided by local authorities. www.familyfund.org.uk – Unit 4 Alpha Court, Monks Cross Drive, Hintington, York, YO32 9NW. 01904 550000

Capability Scotland, Contact a Family Scotland and Sense Scotland all provide advice, support and information to families of disabled children.

- Capability Scotland, 11 Ellersley Road, Edinburgh, EH12 6HY. 0131 3135510 - www.capability-scotland.org.uk
- Contact a Family Scotland, Norton Park, 57 Albion Road, Edinburgh, EH7 5QY. 0131 - 475 2608 - www.cafamily.org.uk/scotland
- Sense Scotland, 43 Middlesex Street, Kinning Park, Glasgow, G41 1EE. www.sensescotland.org.uk