Respite : Definitions and Policy

(A background paper prepared for the MS Society as part of a review of MS Society Holiday Homes)

Rosemary Chesson
Health Services Research Group
The Robert Gordon University

November 2001
## Contents

### Acknowledgements

### Part 1: Definitions of Respite

1. **Introduction**
   - 1.1 Current usage

2. **Respite provision**
   - 2.1 Activities
   - 2.2 Duration

3. **The purpose of respite**
   - 3.1 Who is it for?
   - 3.2 Rehabilitation

4. **Why is a standardised definition required?**
   - 4.1 Shared terminology is necessary for effective communication
   - 4.2 Implications for funding
   - 4.3 Implications for research and evaluation

5. **Steps towards a standardised definition**
   - 5.1 Emerging consensus
   - 5.2 A cautionary note

### Part 2: Respite Policy

1. **Background**
   - 1.1 The growth of respite services
   - 1.1.1 Respite and holiday homes
   - 1.2 Research and the development of respite related policy
     - 1.2.1 Time for a Break (Respite Care): A study of providers, consumers and patterns of use
     - 1.2.2 The Patchwork Quilt
     - 1.2.3 The way forward in Kent
2 Developments of respite related policy

2.1 Early reports and white papers
2.2 The NHS & community care act (NHSCCA)
2.3 Carers (Recognition & Services) Act
2.4 The Scottish Office Social Work Services Group: Guidance on Respite Care (SOSWSG 10/96)
2.5 A National Strategy for Carers
2.6 Current Scottish legislative developments

3 Policy: funding and charging

3.1 Funding
3.2 Charging policies
3.3 Promoting choice

4 Quality of Respite Care

4.1 Care Standards
4.2 Monitoring
4.3 Quality, monitoring and policy

5 Policy and the role of the MS Society

5.1 Contributing to the development of local and national policies
5.2 Developing an MS Society Respite Strategy
   5.2.1 Issues to be addressed
5.3 Endnote

References

Appendix 1 - Search Strategy
Appendix 2 - Inspection Standards (omitted from on-line version of report)
Acknowledgements

I am grateful to Lindsay Mathers, Louise Mitchell and Catherine Murdoch of the Health Services Research Group for help in carrying out the literature searches and commenting on early drafts of this report. Thanks are due also to Heather Cunningham who has processed and produced this report without complaint. I should like, also, to acknowledge funding from the MS Society.

Rosemary Chesson
Reader in Health Services Research
The Robert Gordon University

Cover Design: Lindsay Mathers
1 Introduction

1.1 Respite: Current Use

Following a literature review of respite in 1997, Noble & Bateman concluded that no uniform definition existed. This is still the case today. Lack of consensus is indicative not only of the very wide range of activities incorporated in the term, as demonstrated in section 2, but also of the way respite provision has developed, as outlined in section 3.

The literature search, undertaken specifically for the purpose of this report (see Appendix 1), revealed over 30 different recorded definitions. The search itself, moreover, was problematic because of the diversity in the terms employed, as illustrated in Box 1.

Box 1: Terms in current usage

<table>
<thead>
<tr>
<th>Respite</th>
<th>Short Breaks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite Care</td>
<td>Short Term Care</td>
</tr>
<tr>
<td>Respite Services</td>
<td>Short Term Stays</td>
</tr>
<tr>
<td>Respite Breaks</td>
<td>Interim Care</td>
</tr>
<tr>
<td>Intermediate Respite Care</td>
<td>Respite (Short Term Breaks)</td>
</tr>
</tbody>
</table>

No definitions were found relating specifically to Multiple Sclerosis, or more generally to neurological conditions. Overall, there was little reference to respite for younger people with physical disabilities, reflecting the current nature of respite provision. For example, in Aberdeen although an estimated 85% of disabled people have physical disabilities, less than 8% of all designated respite places in nursing and residential homes are for this client group (Mitchell & Chesson, 2001).

One of the most common points of disagreement is regarding whether or not day care should or should not be included as respite. This is particularly
problematic since the aims of day care itself are often unclear (Nocon & Baldwin, 1998). Although day care may provide for respite, most would agree that this is not its primary function. However, some providers refer to day care as intermediate respite care.

Further confusion is generated by the fact that the term respite care is often used to describe both a service, for example a short stay in a nursing home, and an outcome, such as relief for the family carer (Noyes, 1996).
2 Respite provision

2.1 Activities

Most commentators agree that respite is an umbrella term, referring to a broad spectrum of activities encompassing home based and residential services. In addition respite is offered by a diverse group of providers, including health and social care and the statutory and voluntary sectors.

It is generally acknowledged that respite varies widely according to its nature, circumstances of provision, who it is provided by, or to and when it is available, (Hayes et al, 1995). Lindsay’s description of respite as a ‘patchwork’ service which comprises ‘bits and pieces of other services’ (Lindsay, 1993) has resonance today. In a respite strategy document produced by one Scottish local authority, respite care is outlined as provided by a number of services, either as the main purpose of the service or as a by product. Services of which respite is often a core function are shown in Box 2.

Box 2: Services offering respite care

| Befriending | Shared care |
| Sitter service | Home care |
| Residential respite care | Day care |
| Nursing home respite care |

2.2 Duration

While respite is seen to be provided for a short period of time, and is highlighted in the use of the term ‘short break’, few definitions set time limits.
Exceptions are as follows:

‘This (a break away) may include residential, domiciliary and home-supported assistance. It will not exceed three months for adults’.

(Social Services Inspectorate, 1993)

‘Respite care can be provided within or outwith an individual’s home and may extend from a few hours to a few weeks’.

(Scottish Office, 1996)
3 The purpose of respite

3.1 Who is it for?

There is widespread agreement that respite should be for the benefit of the carer. Indeed, this is apparent in the derivation of the term:

‘. . . . the provision of resources designated to relieve the caregivers of some portion of the normal care activities - that is some form of respite’.

(Zarit, 1990)

In the USA, respite services developed from a need to support the families of developmentally disabled individuals. Moreover, respite provision was regarded as a preventative strategy or ‘treatment’ for dysfunctional family relationships owing to the strain of caring (Smyer & Chang, 1999).

In the UK in 1997 Noble & Bateman concluded from their literature review on respite that most definitions indicated that respite was aimed primarily at a carer on a short term basis. This focus continued to be evident several years later:

‘Some definitions of respite care imply that it is aimed at providing the care recipients with a break from their carers. However, it is generally accepted that it is the carer who is intended as the direct beneficiary, with the aim being to exert a positive effect on their well-being during and after intervention, thus enabling them to continue in their role’.

(McNally et al, 1999)

More recently, Weightman, while recommending a change in terminology to short breaks, observed that the word respite continued to be in usage in many areas to describe carer needs (Weightman, 1999). However ‘respite’ he argues is suggestive that caring is ‘something disagreeable or burdensome’, reflecting a growing body of opinion that the term respite has negative connotations (Nolan & Grant, 1992; Social Services Inspectorate, 1993; Scottish Office, 1996).
While not disputing that carer needs are important, increasingly during the 1990s a new emphasis on the care recipient has developed. This stresses that short term care should provide a positive experience for the person cared for, as well as the caregiver (Weightman, 1999).

Reflecting past emphasis on hospitals and nursing homes as significant providers of respite, commentators have also highlighted that respite has become associated with residential care. Concomitantly it has also led to it being seen as a crisis orientated service. Thus it has been argued that the term respite fails to reflect the nature of new and imaginative services (Hayes et al, 1995) which often emerged following bed reductions in hospitals and means testing in nursing homes. In on-going research based at The Robert Gordon University, Aberdeen, we have found too that the term respite is seen by users as having ‘an institutional feel’ to it and that users distinguish between different types of provision illustrated in the following interview extract:

‘At the moment he goes to a (unit) -  it is really like going to the hospital. At other times of year there is an MS holiday home at Leuchie in North Berwick, and we can either both go there, or in October he is going on his own and that is really nice. That is a holiday, but going to respite care in (the unit) is more like going into hospital’

(Unreported data from Chesson & Garcia 2001)

Indeed a consistent trend in recent years has been to recognise the importance of short breaks in maintaining the quality of life for both carers and those they care for (Scottish Office, 1996). Ashworth & Baker’s work, for instance, revealed the extent to which respite services might enable carers to do things most people take for granted (Ashworth & Baker, 2000), and holiday homes including those supported by the MS Society, often see this as an important part of their work.
3.2 Rehabilitation

Rehabilitation until recently was seldom regarded as one of the aims of respite (Nocon & Qureshi, 1996). However, early in the 1990s some services were set up to enable users to develop independent living skills and to enhance their quality of life (Flynn et al, 1994). These aims, it has been asserted are ‘effectively the same as those of social rehabilitation’ (Nocon & Baldwin, 1998). Indeed, some policy statements also suggest that respite care or ‘short-term breaks’ offer an opportunity to provide rehabilitation, though this is regarded as an adjunct to the breaks, rather than one of their integral functions (Department of Health, 1995). The growth of the provision of therapy, within holiday homes in recent years, would strengthen the argument for their inclusion within the orbit of respite.
4 Why is a standardised definition required?

4.1 Shared terminology is necessary for effective communication

It is evident from recent publications that some confusion exists regarding what respite is. In a recent American study it was concluded that actual respite practice incorporates categories of care that are inconsistent with the standard definition. This is seen as potentially creating misunderstanding regarding respite use in the minds of potential consumers and health care professionals (Smyer & Chang, 1999). In particular, there has been a trend in recent years in Britain for an increasing range of activities to be labelled as respite. The danger exists that as a ‘catch-all’ term respite will cease to have utility as a category for service assessment and planning. The recent move towards use of the term short breaks (Social Services Inspectorate; 1993; Scottish Office Social Work Services Group, 1996) has also added to the confusion. A recent survey by Shared Care Scotland (a national charity for respite) revealed that both respite and short breaks were in common usage and no clear preference regarding terminology emerged (personal communication).

Clearly service users, and especially potential users, need clarity if they are to access respite and to make informed decisions, and choices.

4.2 Implications for funding

In the US, where there is no consistent public or private funding for respite care, it has been claimed that ‘covert mechanisms’ may be used to meet needs. For example, admission by the family physician for ‘medication adjustment’ of the care recipient’s regimen may permit the caregiver to receive ‘respite time’.

Concomitantly, costs may thereby be met by Medicare or Medicaid, as well as through supplementary private insurance. Smyer & Chang (1999) while describing the American situation argue that such strategies ‘mirror the well accepted social relief admission for caregiver strain found in Western Europe’
(Caradoc-Davis & Harvey, 1995). In the UK there is much anecdotal evidence that respite may be provided in NHS hospitals under a similar guise. Indeed, it is acknowledged that charges are an important issue for most carers, and prevent people from using services (Lothian Short Breaks and Breaks from Caring Group, 2001). If, however, NHS beds are not designated as respite places there is a considerable risk that when wards close respite needs will not be adequately met in the community. In fact, Lindsay et al, early in the 90s recommended that a clear definition of respite care in the hospital setting should be devised (Lindsay et al, 1993).

Smyer & Chang (1999) also highlight how terminology may affect funding policy. In the US, they contend many policy makers are opposed to paying for a ‘vacation’ for the caregivers. They propose subsuming respite care within the broader category of interim care. The latter they define as follows:

‘any short-term service that is intended to provide temporary care of an impaired person, including respite care services for the family caregivers . . . .’

(Smyer & Chang, 1999)

This alternative to respite care they believe would ‘help to dispel the idea that respite care is provided for the sheer recreation of the caregiver’.

4.3 Implications for research and evaluation

McNally et al (1999) sought to examine systematically the effects of respite care on carers’ well-being through a review of the literature. Although initially they had hoped to undertake a quantitative synthesis of the data using meta-analysis, they were compelled to adopt a qualitative approach ‘because of the great diversity in study design, types of intervention, settings of intervention and variety of outcome measures’ (own emphasis). The need for shared definitions not only applies to primary research but also to systematic reviews.
5 Steps towards a standardised definition

5.1 Emerging consensus

For a number of years there has been widespread support in the UK for abandoning the term respite. As discussed earlier in this review, the main objections are as follows:

a) respite has come to be associated with carer relief from the burden of caring;
b) respite is often regarded as referring to emergency or crisis related care and may not reflect adequately ‘the nature of the new and more imaginative’ services provided (Hayes et al, 1995);
c) respite has come to relate to institutional residential provision.

Increasingly, service providers are opting to use the term short breaks, for example in a recent working group report the following definition was adopted:

‘the distinctive feature of short breaks and breaks from caring is that the break should be a positive experience for the person who has support needs and the carer (where there is one), in order to enhance and develop the quality of their lives and to support their relationship.

Short breaks and breaks from caring can be provided within or outwith an individual’s home and may extend from a few hours to a few weeks’

(Lothian Short Breaks and Breaks from Caring Group, 2001)

5.2 A cautionary note

Although short breaks is being widely adopted, and may have come to assume political correctness, the term is not without its problems.
Some of these are:

(i) the term is more widely known, understood and used by social care workers, rather than health professionals, and may be confusing to users;

(ii) association with the travel industry’s marketing campaigns promoting weekend breaks may lead to failure to take carers’ and care recipients’ needs sufficiently seriously and may also have funding implications;

(iii) shorts breaks may not sit comfortably with more recent activities associated with respite, for example opportunities for rehabilitation and the education of the carers. Hanson et al in 1999, for example, forwarded the view that the term respite care itself needs to be extended to include the ‘expressed needs of family carers for information, skills, training/education and emotional support’;

(iv) breaks are suggestive of episodes of care rather than continuous service provision, yet current developments stress continuity;

(v) respite provision increasingly is including a diverse range of services and the need may already exist to ensure differentiation between activities. One Scottish local authority has recently documented different types of respite as related to differing client circumstances, as shown in Box 3. The term short breaks in this context may simply not be up to the job.
### Box 3: Types of respite as meeting different circumstances

|**Planned Respite**| Providing planned opportunities for the carer and cared for person to enjoy different activities with different social groups. |
|**Holiday Respite**| Breaks, annually supplied to the cared for person, the duration of which are agreed at the outset. |
|**Emergency Respite**| Provision of care at short notice. |
|**Care at Home**| Extra assistance for families with a family member who requires support with a range of personal care tasks. |
|**Community and Family**| To provide support in the person’s home, or in the home of a substitute carer who is provide respite. |

(South Lanarkshire, 2000)

Although ‘respite’ suffers from past associations, and indeed it has been in use for several decades, proposed alternatives, such as short breaks may be even more problematic. As with the term carer, respite may have its shortcomings, but it is difficult to replace.
1 Background

1.1 The growth of respite services

Respite services first appeared in the early 1970s in the USA as the deinstitutionalisation movement gained momentum (Smyer & Chang, 1998). Similarly in Britain respite services have developed alongside the government commitment to community care. Specifically, this policy has resulted in continuing care in hospitals or nursing homes being regarded as appropriate for only a very small number of people with very severe disabilities. Overall an increasing proportion of local authority funding has been aimed at supporting people to live independent lives in the community (Cumella, 1998).

While initially the mainstay of formal respite was hospital care (Hanson et al, 1999), as hospital beds have been reduced, so domiciliary and home based respite schemes have grown in number. Concomitantly the failure of community provision to keep abreast of hospital closures in the 1990s has led to an increasing number of people assuming ever extending caring roles. This has been seen as helping to place respite high in carers’ campaigning priorities (Lothian Short Breaks Group, 2000).

Reflecting the changing nature of respite, there has been a strong trend towards replacing the term ‘respite’ with ‘short breaks’. This shift in terminology has been seen as ‘symptomatic of a quiet revolution that’s been taking place in the way some social services departments, health services and voluntary organisations have together evolved a much greater range of short breaks for carers and users’ (Weightman, 1999).

1.1.1 Respite and holiday homes

For many years, charities and local authorities have acknowledged that people with disabilities, may not be able to access ‘normal leisure activities’ and holiday facilities and ‘if they are to get away at all, special provision has to be made’ (Weightman, 1999). Indeed, early surveys of
people with disabilities revealed small numbers of respondents had recent experience of a holiday. For example it was reported in the *One in Seven* study that 29% of interviewees with physical disabilities had not taken either a short break or a holiday in the previous three years (Sutherland & Chesson, 1990). Not surprisingly, therefore, members of voluntary organisations have often provided the impetus for the creation of a ‘special holiday home’. Generally, these are located somewhere in the country or by the sea and offer places all year round. According to one holiday home manager, commenting on the role of a National Schizophrenia Fellowship holiday centre:

‘there is a dearth of respite care, apart from hospital, which is not appropriate or residential home accommodation, where there are a number of live-in residents. If you go there for a holiday it can be a bit difficult because you aren’t part of it, whereas everyone’s here for a holiday, and Forresters is run on the lines of a hotel. Anecdotally we know people come here who would otherwise have been admitted to hospital when they didn’t really need to be or alternatively, that people come for planned respite, which actually prevents them breaking down’.

(Anon, 1996)

1.2 Research and the development of respite related policy

There is little British research relating to respite. Differences in terminology, type of provision, duration and care group use has also confounded attempts to establish effectiveness. However, it is important to note in the policy context that there have been two major government funded research studies; the earliest in England, and more narrowly focused, and the second in Scotland. Both are described in more detail below since they have been influential in shaping both central and local government strategies yet the recommendations of both have yet to be fully implemented.
1.2.1 *Time for a Break (Respite Care): A study of providers, consumers and patterns of use*

This Department of Health funded study by Robinson & Stalker followed Robinson’s earlier work on respite for Bristol and Western Health Authority (Robinson, 1987). The main aims of the study were to describe the nature and context of respite care services available for young people (up to 20 years), including hospitals, hostels and family based schemes, in three local authority areas (Croydon, Sheffield and Somerset). The experiences of 586 children and young people were documented and the main conclusions from the study were:

- that there was poor record keeping of client information and of services received, as well as non-standardised recording and classification of use;
- approximately 1 in 5 children were receiving services from more than one provider;
- 43% of families indicated the need for more services, mostly respite due to current inadequacies of provision;
- 20% were highly critical of current respite provision and there was a lack of knowledge of respite;
- respite was seen as beneficial to families and the young person concerned;
- barriers to respite uptake were identified as concerns over the disruption of the child’s routine and fears of long term care.

(Robinson & Stalker, 1989)

While this early research relates specifically to children, many of the issues raised have been highlighted in numerous subsequent studies, across a range of care groups, over the last decade. Despite many local authorities attempting to address problems associated with respite provision, few have put into place coherent comprehensive strategies. A frequently expressed view is that the lack of reliable statistical data regarding respite is an obstacle to policy development not least because it
inhibits financial planning. Thus of considerable interest is the work of Lindsay et al in Scotland in the mid 1990s.

1.2.2 *The Patchwork Quilt*

This study by Lindsay et al (1993) was funded by the Scottish Office to determine the range, volume, style and costs of respite care services in Scotland. The investigation covered respite provided away from home in residential, hospital or family based services, as well as support delivered at home through domiciliary services. Day care was not included. The report focused on five main care groups: older people; people with dementia; people with mental health problems; adults and children with learning disabilities; and adults and children with physical disabilities. The overwhelming picture which emerged, was of considerable variation in provision. Specific findings are presented below:

- nearly 800 residential establishments offered respite care, with 320 having beds designated for that purpose;
- eighty-six hospital units who responded provided respite care;
- of nearly 800 residential services, 80% were for elderly people and 14% for people with learning disabilities;
- only 4% of residential services were ‘respite only’ services;
- while it was difficult to estimate the number of people receiving respite care in hospital it was concluded that a substantial number of people (perhaps 5 - 6000) received this service;
- people with physical disabilities tended to receive respite care alongside other groups with whom they have little in common, in hospital or nursing homes. The number of places was very limited and there were very few specialist services;
- information on the costs of respite care was very limited and sources of funding vary considerably. Insecurity of funding was seen to inhibit developments;
- unit costs of residential respite care were significantly higher than for permanent care.

(Lindsay et al, 1993)
One of the main recommendations made in the *Patchwork Quilt* was that the respite needs of people with physical disabilities should be addressed, as very little specialist provision was available.

Although the findings of Lindsay et al, 1993 underpinned the production of the *Scottish Office Social Work Services Group Guidance on Respite Care*, it did not lead to a national policy on respite. However, the recommendations (as discussed in section 2) provide an excellent policy framework and await incorporation into community care legislation.

A further relevant policy-related investigation, especially regarding holiday respite, is that carried out by Kent Action on Respite Choice (KARC).

1.2.3 *Respite: The way forward in Kent*

Following an earlier research project in 1995, KARC began new work funded by Kent Social Services and East Kent Health Authority, with a contribution from West Kent Health Authority carried out by Noble & Bateman, in 1997. The aims of the research were to: (a) establish a common understanding of the principle of respite; (b) identify the respite needs of disabled people and carers in Kent; (c) identify the resources required to meet needs; (d) make flexible and innovative recommendations.

Adults with physical disability were one of the six priority groups focused on by the researchers.

Seventy per cent of the respondents agreed with the KARC definition of respite, namely ‘giving carers and the disabled the chance to have a break from their normal routine, to learn skills, start new hobbies and broaden their social horizons’. Some alternative suggestions, forwarded by respondents included ‘respite should allow me the chance to have some rehabilitation; and respite should prove to be mentally stimulating’ (Noble & Bateman, 1997). The main conclusions from the study are shown in Box 1.
Finally, respondents told KARC what opportunities they felt respite should offer them. These included: more affordable respite breaks; more holiday respite; more mental relaxation; and the chance to lead a normal life (Noble & Bateman, 1977).

It is important to note that many of the recommendations forwarded by KARC continue to be incorporated in respite strategies, but not implemented.

Box 1: Respite: The Way forward in Kent

Conclusions:

- There is a lack of information about the availability of respite breaks. Too many carers and disabled people have not heard of respite. The provision of emergency respite is inconsistent and inflexible to need.

- A number of respite providers are not supplying an innovative, life enhancing service. There is a potential for diverting statutory sector resources towards more innovative forms of respite provision.

- There is a high demand for more leisure respite from disabled people in Kent. Holiday respite is not being used by disabled people and carers who might benefit from its provision for reasons such as lack of accessibility and flexibility of existing services.

- There are seasonal variations in the demand for respite breaks.

- Transport difficulties can deter disabled people and carers from using respite services.

- Hospital respite is perceived in a very negative way, especially by carers.

- There is not standard definition for respite.

- A number of carers have serious problems, which either stem from or are made worse by caring.

(Noble & Bateman, 1997)
2 Development of respite related policy

Currently no specific central government policy exists regarding respite care. However, several government policy documents relating to community care make reference to respite care. These are shown in Box 2 and are discussed below. In this report aspects of policy most relevant to people with MS have been the main focus.

2.1 Early reports and white papers

One of the earliest references to respite was by the Joint Central and Local Government Working Party on Public Support for Residential Care, reporting in 1987. Respite was identified as one of many facilities (including domiciliary and day care) provided by statutory and independent agencies as helping people who are ‘old, disabled, sick or incapacitated’. Significantly respite or ‘short term care’ was described as to be used as follows: ‘to provide relief for carers, for assessment in a residential setting, to provide opportunities for rehabilitation or to provide immediate response to a crisis’.

The working party recommended that the funding system for respite care ‘needs to be flexible’ in order to facilitate speedy decision making and to ‘allow respite care to be provided as part of a package of care’ (Joint Central & Local Government Working Party, 1987).

These recommendations were endorsed in the following year in the Griffiths Report, and reflected in the subsequent white papers Caring for People and Working for Patients. Key objectives listed in Caring for People included:

- Promoting the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible.
- Ensuring that service providers make practical support for carers a high priority.
### Box 2: Key government policy documents relating to respite

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1988</td>
<td>Community Care: Agenda for Action (The Griffiths Report)</td>
</tr>
<tr>
<td>1989</td>
<td>Working for Patients (Department of Health) Caring for Patients (Scottish Office)</td>
</tr>
<tr>
<td>1990</td>
<td>NHS &amp; Community Care Act</td>
</tr>
<tr>
<td>1995</td>
<td>Carers (Recognition and Services) Act</td>
</tr>
<tr>
<td>1996</td>
<td>Community Care in Scotland: Guidance on Respite Care (Circular SOSWSG 10/96)</td>
</tr>
<tr>
<td>1999</td>
<td>Caring About Carers: A national strategy for carers</td>
</tr>
</tbody>
</table>
2.2 The NHS & Community Care Act (NHSCCA)

This became law in 1990 but was implemented in April 1993 and incorporated many of the proposals of the earlier 1989 white paper. In particular, the Griffiths Report (1988) had proposed that the primary role of social services departments should be to identify need and purchase a ‘mixed economy’ of social care. Furthermore as new applicants took up residential and social care there would be a progressive transfer of funds from social security to local authority budgets. Central government specified that a minimum of 85% was to be used to purchase services from the independent sector. Cumella has commented that ‘this gave a strong incentive to local authorities to transfer the provision of services to the independent sector, and in effect to shift from a mixed economy of social care to one with little or no local authority provision’ (Cumella, 1998).

Furthermore, while before the NHSCCA responsibility for planning and development in community care services has been seen as a joint responsibility of local authorities and health authorities/boards, the Act gave local authorities the lead role for community care services. In particular, it required them to produce an annual community care plan identifying local needs and priorities. In fact, today, community care plans may be the best source of information on a local authority’s respite strategy since so few have respite policy documents.

The Act has also had considerable repercussions in continuing care. It resulted in a boundary being created between people with specialist medical nursing needs (identified as an NHS responsibility) and the remaining population in nursing homes.
2.3 **Carers (Recognition and Services) Act**

This had twofold significance in providing one of the few legislative definitions of carer and establishing the carer’s right to an assessment. A carer was defined as an individual who ‘provides or intends to provide a substantial amount of care on a regular basis for the relevant person’. Also under the Act it became possible for a carer to obtain an assessment in the context of the recipient’s care assessment.

The potential of the Act moreover, should not be underestimated since it brought about a shift in the position of carers (South Lanarkshire Council, 2001). Namely, for the first time legislation attempted to address specifically the needs of the carers and the first steps were taken to define the rights of carers. Indeed, the legislation in itself brought rights for carers since it created the right for them to have an assessment of their own, albeit in limited circumstances.

2.4 **The Scottish Office Social Work Services Group: Guidance on Respite Care (SOSWSG 10/96)**

This is one of the very few government policy documents, which directly address respite. It was produced, moreover, because evidence indicated that local agencies were not developing respite care services. In addition, the paper was written in response to local social work authorities and ‘others’ request for guidance. Circular 10/96 has considerable significance because of the emphasis which it placed on respite and the clarification of funding arrangements it provides. It highlighted also ‘the absence in most areas of a clear strategic framework for the provision of respite care’. Specifically it is stated that:

‘The government recognises that respite care is an integral and central part of the range of health and social care services, which ought to be available to persons with community care needs, and also that the demand for respite care is substantial’.
2.5 A National Strategy for Carers

*Caring About Carers* paved the way for more recognition and support to be offered to carers and thus also provided an impetus for the recognition and development of respite services. The Carers Strategy offered specific measures for carers in England and the Scottish Executive subsequently published a Carers Strategy specific to carers in Scotland (a strategy for Wales is to be published shortly). Compared with the *Guidance on Respite* (1996) the National Strategy for Carers had much more emphasis on making services as accessible as possible for carers. If achieved, therefore, this would enable more people to keep on or take up caring responsibilities in the future. Fundamental to both strategies was a government commitment to supporting carers.

Following the Scottish Carers Strategy, a Scottish Carers’ legislative Working Group was established. This concluded that ‘a number of very practical changes’ had already resulted from the strategies and that ‘radical changes in legislation’ were not needed to effect change. Rather it was argued what was needed was for redefinition and clarification of the way ‘carers are viewed’. It was proposed that the most significant changes to the position of carers could be made through formal recognition that ‘carers are providing support, not consuming services’. In the report of the Working Group the view was unequivocally expressed that:

‘crucially, the recognition of carers, as partners with other providers of care will underline to statutory agencies the central role played by carers and the need for them to act in partnership and complementary support with carers. Like all other care providers, carers require resources to provide support. What many carers need most are regular short breaks ... from the demands of caring in order to be able to carry on again’.

(Scottish Carers’ Legislation Working Group, 2001)
An area where the Working Group believed the law should be changed was regarding carer assessment. It was recommended that legislation be amended so that carers are entitled to an assessment in all circumstances i.e. regardless of whether the cared for person is being assessed. Furthermore, it was suggested that a statutory duty should be placed on local authorities to provide information to carers about their rights and support options, and to offer assessments to carers.

A consultative document was issued in July 2001 and currently a government response is awaited. It is evident, however, that the Scottish Parliament has been proactive in the drafting of new social and community care legislation. Currently there are several Acts awaiting consent, which relate to respite and these are briefly considered below.

### 2.6 Current Scottish legislative developments

**Community Care & Health Bill:** The most publicised aspect of this Bill, which will be implemented in April 2002, is that it will allow people to receive free personal care as well as nursing care in care homes (BBC News Online, 2001). However, the Bill will also formalise joint working between health boards and local authorities, including joint funding and management of health and social care services. In addition, the Bill extends the right of carers to receive a carer’s assessment, by making it possible for them to receive a carer’s assessment even when the person being cared for does not wish to be assessed.

**Regulation of Care (Scotland) Act 2001:** Again due to be implemented in April 2002, this Act will establish two new independent bodies: the Scottish Commission for Regulation of Care and the Scottish Social Services Council. The Commission will regulate and inspect all care services, including residential and nursing homes, referred to as ‘care homes’, as well as home-care services. As part of this, Draft National Care Standards were issued in stages (for different care groups) from June 2000 and a consultation paper on care homes was issued in April 2001.
Scottish Executive Response to the Report of the Joint Future Group:

This report, published in January 2001, is the Scottish Executive’s response to the Report of the Joint Future Group (2000), which recommended improvements in joint working between health and social care departments. The report again reiterates the Scottish Executive’s commitment to providing more short breaks. In particular it acknowledges continuing levels of unmet need. It estimates that of 150,000 carers who provide more than 20 hours a week of care, half have not had a break for more than two days since beginning to care. It also identified a need for more ‘effective and personalised short break services - at home - to widen choice as part of a continuum of care’ (Scottish Executive, 2001a).

Local Outcome Agreements: A joint approach with the Convention of Local Authorities (CoSLA) launched in July 2001, Local Outcome Agreements are an attempt to relate Scottish Executive Ministers’ national policies to specific local service targets (Scottish Executive, 2001b). Although currently being piloted in the areas of education attainment in schools and children’s services, the Executive has also indicated that they may be used for other priority areas. At a Shared Care Scotland Conference in October 2001, the Head of the Scottish Executive Community Care Division, Thea Teale, stated that the Outcome Agreements must indicated specific outputs, for example, the number of weeks respite care will be provided, and must show consultation with carers and users.

As can be seen from the above, carers’ issues and respite provision are areas that are developing rapidly. Funding arrangements are fast evolving, and attempting to address areas which historically have been problematic. In the following section funding aspects of policy are outlined.
3 Policy: funding and charging

3.1 Funding

It is important to note that although the NHSCCA may have led to a more systematic approach to priority setting and social care planning it has not provided people with a disability with an *entitlement* to health and social care services, nor any *consistent access* to treatment and care in different parts of Britain (Cumella, 1998) [own emphasis]. Moreover, the issue of appropriate charges for respite services has to be seen in the wider context of community care charging policies.

Services which are directly or indirectly relevant to respite provision are provided by both the statutory and non statutory sector including funding from: health authorities and boards; social services/social work departments; government grants allocated for specific care groups or medical conditions; and special projects. Over recent years voluntary sector provision has increasingly been funded by grants from the Community Fund (formerly the National Lottery Charities Board) as well as from local government sources.

While social work authorities most often have had the lead responsibility for arranging and funding respite care, health purchasers are expected to fund short-term health care where the recipient’s health requires it. However, during the 1990s it has been increasingly emphasised that short-term care previously provided by the NHS for people ‘whose needs are predominantly for social care’, should be purchased from social services/social work departments. Of interest in delineating this policy, the Guidance provided by the Scottish Office states:

‘the scope which the NHS now has to meet a local need for social respite care in the *margins of its provision of long stay care* will reduce and will, in time, cease as services are reprovided and firmly established in the community’ (Scottish Office, 1996) [own emphasis].
Currently, however, it appears that funding to local authorities from central government for community care itself may be insufficient, because grant aided expenditure has not been able to keep pace of inflation. *The Carers Strategy* has led to increased funding of respite, for example in Lothian in the year 2000, 62% of the half million pounds allocated for the development of carers’ services was awarded to Short Breaks Services (Lothian Short Breaks Group, 2001). Fears exist that new developments can only be resourced through taking funding from existing services.

The need for respite budgets to be ring fenced has also been highlighted. In addition, The Scottish Joint Future Group (2000) has recommended that ‘resources need to be dedicated to short break support and not to any specific provider, such as a residential nursing home’.

It has been claimed that in future years direct payments by the user will account for an increasing proportion of funding for respite. Furthermore some see the *National Strategy for Carers* recommendation that carers should be enabled to take up paid employment, as being driven by the aspiration that carers will be better able to afford the services they require (Lothian Short Breaks Group, 2001).

In the years following the Report of Joint Central and Local Government Working Party on the Funding of Long Term Care (1987) there has been increasing endorsement of the recommendation that the funding systems for respite care need to be flexible, so that decisions can be made quickly. However, agreement is lacking regarding the best means by which this may be achieved. In the Scottish Office Circular of 10/96, for instance it was argued that although spot purchases (i.e. for one or a few identified users for specified periods as the needs arises) may appear to maximise flexibility in offering choice, in practice this may not necessarily be the case. Block purchasing (i.e. commitment in advance to purchase places for an external period for users not at that stage identified) was regarded as preferable. This is seen to have the advantage of offering continuity of care for the user, better planned care and encouraging the development of specialist respite care.
Furthermore the Scottish Office were of the opinion that:

‘cumbersome arrangements for assessment of ability to pay, and charging policies which discourage the use of effective respite services are not in the best interest of users, carers or providers or of local authorities’ effective use of resources’.

(Scottish Office Social Work Services Group, 1996)

3.2 Charging policies

A Scottish Consumer Council survey of local authority practice in providing information about charges for non-residential community care services undertaken in 1999 found that some authorities had highly complex charging policies. In addition, they found that five of the 25 authorities which responded reported that in carrying out financial assessments they took account of financial resources of people other that the service user (for example a partner or spouse). Yet it is noted that this is ‘contrary to the law and to government guidance’. In conclusion the Scottish Consumer Council recommends that the Scottish Parliament should consider whether charging for non-residential care services should be subject to national guidance in the same way as residential care (Macdonald, 1999).

Although charges to carers and the people they care for can be reduced if services are accessed through community care assessments, it has been claimed this can restrict flexibility in use.

Regarding holiday respite, the Lothian Short Breaks Group have highlighted how charges for residential respite can be particularly ‘burdensome’. It is pointed out that a holiday for a carer can incur three separate costs, namely normal housing costs, respite costs for the cared for person as well as the carer’s own holiday costs (Lothian Short Breaks Group, 2001).
3.3 Promoting choice

Currently the Carers and Disabled Children Act 2000, which applies to England and Wales enables local authorities to issue vouchers to carers and care recipients, in order to give them flexibility about the arrangement of short breaks, enabling community care services to be purchased. Such an arrangement is at present being considered by the Scottish Carers’ Legislative Working Group. However, Scottish local authorities already have a power to offer ‘eligible people’ direct payments, instead of arranging services, so that they can ‘use the money to purchase for themselves the services they are assessed as needing’ (Scottish Executive, 2001a). The Better Care for All Futures Group proposed, in fact, that each local authority be required to set up a direct payments scheme for all client groups by the end of 2002.
4 Quality of Respite Care

4.1 Care Standards

During the last decade increasing importance has been attached to ensuring that high quality community care services are provided. Notably, over the years an infrastructure for monitoring has become established and increasingly detailed standards of care have been produced. Reflecting this, while standards for respite are still in their infancy, there has been growing agreement regarding what these should be. Early broadly based recommendations have been steadily built upon over the years. Lindsay et al (1993), for instance, in the *Patchwork Quilt*, identified the three key indicators of quality in respite care as being:

1) flexibility of service;
2) accessibility of service;
3) partnership between carer, the person who requires care and service provider in the planning and delivering of the service.

The SOSWSG, in 1996, listed Indicators of Good Respite as shown in Box 3.

In recent years detailed standards have been produced and disseminated including those published by The Scottish Office Social Steering Group for carer support services in 2001 (Box 4). The Department of Health and Social Services Inspectorate’s 1999 standards relating specifically to Short Breaks for people with physical disabilities and older people are reproduced in full in Appendix 1.
Box 3: Indicators of Good Respite

♦ **Is needs-led:** meeting the needs of both users and carers, who should be fully involved in designing packages of care.

♦ **Is planned:** but flexible enough to accommodate emergency situations.

♦ **Is flexible:** provides choice and meets individuals’ changing needs but is also predictable and reliable.

♦ **Forms part of a continuing programme of care:** it is monitored and reviewed as part of that process.

♦ **Provides feedback to the carer:** on what has happened during respite and enables the carer to resume or, with suitable training and support, expand and optimise his or her caring role.

♦ **Takes account of the information and support the primary care health team can provide.**

♦ **Is accessible:** information about the range of services, eligibility criteria and their cost should be made available.

♦ **Is provided in a range of settings:** for example, residential care or nursing homes, supported housing, day care, and individual’s own home or someone else’s home, hospitals (including community hospitals).

♦ **Incorporates arrangements to ensure that both groups benefit where respite and long term users mix:** (e.g. in residential care and supported housing).

♦ **Provides value for money:** in relation to other forms of support when viewed as part of a programme of care.

♦ **Is affordable:** charges to users should not discourage the use of effective services.

♦ **Has benefits for both users and carers.**

♦ **Is a partnership:** providers, users and carers should be at the heart of the design and delivery of services. The provider should elicit the views of consumers on a regular basis and inform them of their role in influencing the service. Feedback should be sought and geared to the abilities and interest of the service users, e.g. focus groups, one to one interviews, questionnaires, and representation on committees.

(Scottish Office Social Work Services Group, 1996)
Box 4: Quality Standards for Local Carer Support Services

<table>
<thead>
<tr>
<th>Standard 2: Providing a Break</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any service offering a break* to carers works in partnership with the carer and person being supported, is flexible and gives confidence and can be trusted</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Works in partnership</td>
</tr>
<tr>
<td>♦ The service respects the carer and caring relationship and fully consults and involves the carer and person being supported</td>
</tr>
<tr>
<td>♦ The service has an agreed process for dealing with any conflict between the carer and person being supported should this arise</td>
</tr>
<tr>
<td>♦ Full information is provided about the service and opportunities to meet staff or visit the service before the carer and person being supported make any decision</td>
</tr>
<tr>
<td>♦ Feedback is encouraged from both the carer and the person being supported</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Flexible and adaptable to the carer’s needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ The service is suited to the assessed needs and wishes of the carer, which includes their cultural and religious needs</td>
</tr>
<tr>
<td>♦ The service is flexible and can time services to suit the carer. Wherever possible the service should operate at night, over public holidays, offer mid-week starts and non-standard length breaks. At a minimum the service should make every attempt to negotiate the best possible arrangements with the carer.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The service gives confidence an can be trusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ Carers say that they get peace of mind where the service:</td>
</tr>
<tr>
<td>⇒ Is sensitive to the age, gender, sexuality, disability, religion, ethnicity and personal needs and choices of the person being supported</td>
</tr>
<tr>
<td>⇒ Provides a stimulating, not simply safe, environment which fosters independence and well being, whether it is in a residential home, day service or offered through one-to-one care in someone’s own home</td>
</tr>
<tr>
<td>⇒ Provides personalised care in a friendly welcoming atmosphere where individuals are treated with dignity and respect and privacy is maintained</td>
</tr>
<tr>
<td>⇒ Ensures the quality of care is consistent from one break to the next and wherever possible provides the same paid care worker or at the minimum someone previously known to them</td>
</tr>
<tr>
<td>⇒ Meets the person’s preferences in the way personal care is provided (ensuring this does not conflict with the need to safeguard the health and safety of the person delivering the care)</td>
</tr>
<tr>
<td>⇒ Properly looks after clothes and personal possessions</td>
</tr>
<tr>
<td>⇒ Ensures paid and volunteer workers going into people’s homes and in residential and day care facilities are appropriately trained, understand what it is like to be a carer, are supervised and relevant security checks undertaken</td>
</tr>
</tbody>
</table>

(Quality Standards Steering Group, 2001)

* These services may be provided at home, in day or residential facilities, in community, leisure or holiday settings, or in other people’s homes and include services which provide opportunities for the carer and person being supported to go away together. These are services, which provide a real break and “time off” for the carer, not an emergency response when there is a crisis.
4.2 Monitoring

The National Care Standards Commission will be established from 1 April 2002 as a non-departmental public body to take on the regulation of Social Care and private and voluntary health care in England. Part of its remit will be to regulate and inspect these services against national minimum standards. In Scotland, The Scottish Commission for the Regulation of Care will also become operational on 1 April 2002 with a broadly similar remit to its English counterparts. In addition to its regulatory functions, the Commission will have other responsibilities including:

- to keep Scottish Ministers informed about the provision and quality of care services in Scotland
- to encourage improvement in the quality of services
- to make information available to the public about the quality of care

4.3 Quality, monitoring & policy

Best practice needs to be identified and promoted in all policy documents both at local and national levels. Monitoring undoubtedly is vital to ensure that services are meeting the standards set. Clearly it will be important for any policy developed by the Society to address quality and monitoring issues.
5 Policy and the role of the MS Society

From the previous review of policy it is evident that there are two main roles for the Society: (1) contributing to on-going debate regarding both local and national policy; and (2) developing the Society’s own respite care policy. These are discussed further below.

5.1 Contributing to the development of local and national policies

As currently there is no national policy framework, the Society is an excellent position to contribute to forthcoming policy documents.

At a local level, a first step may be to achieve input into local community care plans, which all local authorities must publish. Indeed, the needs of carers should be considered within plans. In addition, it will be important to ensure consultation regarding the production of local respite care strategies. Since few local authorities have produced strategies, the society could attempt to encourage their production and ensure that they adequately meet the needs of the Society’s members. Given the dearth of reliable information on respite provision (Mitchell & Chesson, 2001) the Society could also help to initiate information systems locally which indicate the nature and extent of local respite provision. A particular concern would be to ensure that residential and emergency provision in particular, is appropriate for people with multiple sclerosis, and is not for example, provided within a Care of the Elderly setting.

5.2 Developing an MS Society Respite Strategy

Listed overleaf are some of the main issues which would need to be addressed in any forthcoming Strategy Document. It should be recognised that more detailed recommendations cannot be provided since a Strategy would need to be produced in consultation with members.
5.2.1 *Issues to be addressed*

a) How respite is to be defined, what it is, and which terminology is to be employed

b) The main principles by which services are to be provided, such as
   - sensitivity to individual needs, wishes and aspirations
   - treating people with courtesy and respect, including recognition of cultural and religious needs
   - recognition of carers as partners
   - respect for privacy
   - confidentiality

c) How people with MS and their carers’ needs are to be assessed

d) How respite services are to be accessed and the role of the Society in extending accessibility

e) Charging policies for services both provided by the Society, and local authorities and other voluntary organisations

f) How joint working between the statutory and non statutory sectors be promoted to meet respite needs

g) The availability of different types of respite, for example residential, emergency, domiciliary and holiday respite to people with MS and their families and how to ensure equity across the UK

h) Opportunities for rehabilitation within respite facilities

i) The accessibility and availability of opportunities to provide respite in commercial settings
The provision of transport needed by users of respite services

The training needs of staff involved in the provision of respite care

How respite services are to be monitored

Information on respite services and its dissemination (this may need to be addressed by a separate strategy)

Accountability

The above, however, should be regarded as indicative rather than exhaustive.

5.3 Endnote

This policy review on respite was initiated by the Society’s wish to evaluate the cost effectiveness of Society funded holiday homes. However, it soon became apparent that it was essential to extend the brief by considering other relevant social care legislation.

This document demonstrates that policy on holiday homes can not be considered in isolation to the wider issue of respite provision. However, never before has so much attention been paid by local and central government to the needs of carers. It would be timely, therefore, for the Society to have an increasing interest in carers issues, as well as respite, to ensure that members’ needs are met. Nevertheless, an obvious key role for the Society is to ensure that specialist respite services are provided which are affordable and meet members’ wishes and aspirations. Policy, specifically, regarding holiday homes will be examined in the following report, which will present an evaluation of Scottish holiday homes. In conclusion, it is important to note that holiday homes have barely been considered in local and national respite strategies, yet have a potentially important part to play in respite provision.
References


Caradoc-Davis T H & Harvey J M (1995) Do ‘Social Relief’ admissions have any effect on patients or their caregivers? Disability and Rehabilitation, 17, 5: 247-251.


South Lanarkshire Council (2000) *Approaches to Respite Care: In South Lanarkshire*. Lanarkshire: South Lanarkshire Council.


Appendix 1

Search Strategy

1 Literature searches were performed using the following databases:

- Medline 1989 - 2000
- CINAHL 1989 - 2000
- ASSIA 1990 - 2000
- British Nursing Index 1990 - 2000
- BIDS 1995 - 2000
- Cochrane Collaboration of Systematic Reviews (MS Group) Issue 1: 2000

2 Other databases searched included: Caredata, CRD, HEBS, SHOW, SOSIG.

3 Hand searching supplemented database searching.

4 The search was confined to English language reports.

5 Key terms employed were: carer; caregiver; caring; carer well being; burden of care; respite; respite care; respite services; short breaks; multiple sclerosis; neurological disease.
Appendix 2

This appendix provides a reproduction of the Social Services Inspectorate report “Inspection Standards for Short Term Breaks for People with Physical Disabilities and Older People” in the printed version of this report. A copy of the SSI document can be obtained at:

http://www.doh.gov.uk/pdfs/stand2.pdf