



# Developing Services for Older People and Their Families

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## The Evolution of Daycare Services for People with Dementia

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Daycare services in the United Kingdom have developed in a piecemeal fashion with little co-ordination between service providers, and great disparity in the level of provision between regions (Tester 1989a,b). *Caring for People* (1989), the Government White Paper outlining community care policy as legislated in the NHS and Community Care Act (1990), emphasises the importance of daycare in enabling older adults to continue living at home and in providing informal caregivers with a regular break.

Daycare services are widely used by people with dementia. A recent survey in three areas in England showed that 67 per cent of a sample of people likely to have dementia regularly attended such services (Levin, Moriarty and Gorbach 1994). The survey also showed that daycare was wanted and appreciated by caregivers and that there was considerable underprovision of service. In this chapter, the potential benefits of daycare for carers and individuals with dementia are described. Current service provision and research on the effectiveness of daycare services are outlined. More innovative models of daycare are given and components of good quality daycare, as identified in a recent Australian study, are summarised. Finally, the implications for policy and practice are discussed.

A frequently quoted definition of daycare is that given by Tester (1989c):

'A day care service offers communal care, with paid or voluntary caregivers present, in a setting outside the user's own home. Individuals come or are brought to use the services which are available for at least four hours during the day.' (p.37)

The definition excludes purely educational or social settings. It is an arbitrary definition and may serve to create false boundaries, for example by excluding services providing care for shorter periods of time. However, the definition encompasses most of the daycare services described below.

### Potential benefits of daycare services for people with dementia

The basic impairments occurring in dementia include amnesia, disorientation and loss of drive and motivation. As a result of these symptoms, as well as their attempts to adapt to them, people with dementia tend to become socially isolated, to adopt a restricted routine and to stop participating in their favoured interests and activities. Other common sequelae of dementia include poor nutrition, poor hygiene and failure to take prescribed medication. Ideally, people with dementia need support in maintaining as active a life as possible, as close as possible to the lifestyle they would normally have led. Daycare can fulfil a number of functions in strengthening remaining skills and compensating for lost abilities. Activities are an important means of enhancing self-confidence and self-esteem, a way of maintaining cognitive skills as well as a means of assessment and of managing challenging behaviour (Archibald 1990). Daycare services can provide activities which are appropriate to the individual in type and skill level required. The reduction in social isolation through daycare attendance can improve mood and well-being. The provision of meals can help to improve the general health of the person with dementia and prevent the development of diseases associated with dietary deficiencies. Finally, daycare can provide a focus in the life of the person with dementia, a source of pleasure and enjoyment and a place where he or she can feel accepted.

### Potential benefits of daycare services for the informal caregiver

Caring for a person with dementia is acknowledged to be a very stressful process, probably more stressful than caring for people with other disabilities (Gilhooly *et al.* 1994). The stress process itself is determined by a number of variables, including the social and economic characteristics of the caregiver, the nature and magnitude of the care required, role strains including inter-personal conflict, individual coping style and the extent of social support (Pearlin *et al.* 1990).

ACTIVITIES

IMPROVE  
SOCIAL  
WELL-BEING  
GENERAL  
HEALTH  
PREVENT  
DISEASES  
ASSOCIATED  
WITH  
DIETARY  
DEFICIENCIES

Regular attendance of the person with dementia at daycare gives the carer a regular break. As outlined by Levin and colleagues, it is greatly appreciated by caregivers, a higher value being placed on day care than on other community services (Levin *et al.* 1989). It can foster the caregiver's confidence by linking him or her with professionals who see their relative regularly for considerable lengths of time. In Levin and colleagues' most recent study of caregivers, daycare was the main service giving caregivers of people likely to have dementia a regular weekly break (Levin *et al.* 1994). The break enabled them to carry out everyday activities such as shopping, paying bills, going to the hairdressers and visiting friends. In many cases it was preferred to a sitting service as it provided a longer break and offered more choice over whether to stay at home or go out. In addition, many daycare services have regular carers' groups which are an important source of support. Daycare can thus have an impact on the stress process through reduction in the magnitude of care required, through social support to the carer and perhaps also through enhancing the carer's coping style.

#### **Current models of daycare**

##### *Generic day centres for older adults*

Local authorities and voluntary or non-profit-making organisations run daycare services in residential homes and, more frequently, in stand-alone day centres for elderly people in general. Of the total number of day centre places available in England and Wales, local authorities provide approximately 77 per cent and voluntary organisations 23 per cent of places per day (Tester 1989b).

Although some people with dementia attend local authority and voluntary day centres, these do not cater specifically for them and include severe dementia, wandering and behaviour problems among important reasons for refusal of admission (Tester 1989b). People with dementia are frequently not accepted by other attenders. In an in-depth study of 14 day centres in Queensland and Victoria, Australia (Davison *et al.* 1994), the authors concluded that people with dementia were often marginalised in generic day centres, participating minimally in activities which were frequently inappropriate to their abilities. In turn, carers were reluctant to leave their relatives when they were not confident that the day centre would be able to cope. The specific needs

of people with dementia were not being met mainly because staffing levels were too low and staff frequently lacked the required expertise.

##### *Dementia focused daycare*

The specific needs of people with dementia are increasingly being addressed within generic day centres through the provision of day care for people with dementia on separate days or by the allocation of a proportion of the available places to people with dementia. The Dementia Services Development Centre has reported on the Broomhill day centre in Lothian region in Scotland which allocates 20 per cent of places to people with dementia (Lardner, Reed and Suttle 1991). It successfully integrates people with and without dementia for all its activities. Its success is partly due to high staffing levels including a large complement of volunteers, an acknowledgement of the specific needs of people with dementia and the early stage of referral of those people who have dementia so that acceptance by other attenders occurs before memory impairment and other problems related to dementia become very marked.

##### *Dementia-specific day centres*

In Scotland there has been a slow expansion in the number of day centres providing care specifically for people with dementia. Run mainly by voluntary organisations, often in borrowed premises, many provide day care only one or two days a week. However, some have their own premises and paid members of staff and can provide daycare for up to seven days a week. This has the potential advantage of avoiding attendance at multiple venues if frequent daycare is required. Staff can build up expertise over time in the management of more challenging behaviour and facilitate good care management through liaison with other service providers in the area. In the recent Australian study of day centres (Davison *et al.* 1994), staff in dementia-specific day centres were more knowledgeable about dementia, better trained and more skilled in the management of challenging behaviour than staff in generic centres. Their attitudes towards people with dementia were more positive and people with dementia were more likely to receive appropriate care. However, the study indicated that day care in generic settings can be appropriate in the earlier stages of dementia when some people may perceive attendance at a day centre specifically for those with dementia as stigmatising and unacceptable.

*Day hospitals*

Day hospitals are an integral part of most geriatric medical and old age psychiatry services. They are funded by the National Health Service and are staffed by a multi-disciplinary team including doctors, nurses and occupational therapists. While accommodating those who have a dementing illness in addition to physical problems, geriatric medical day hospitals exclude those whose predominant problem relates to their mental state (Tester 1989). In most areas they do not provide significant amounts of daycare to people with dementia.

*Day hospitals in old age psychiatry*

Most of the daycare specifically for people with dementia in Scotland is provided by old age psychiatry day hospitals (Lardner 1991). The day hospital has a number of short-term functions including assessment, treatment and rehabilitation of older adults with dementing illnesses, depression and a range of other psychiatric disorders. It also has a longer-term role in monitoring and treatment and in the provision of relief to informal caregivers. The latter role evolved at least partly due to the lack of any alternative forms of daycare available. Day hospitals with their staff mix have a clear role in the longer-term support of people with dementia who have more severe behavioural problems or mood disturbance, those who are highly dependent on others and those who have complex physical problems. However, for many people with dementia, longer-term support could be provided closer to home, in smaller, non-clinical settings. There is currently an impetus for a reduction in day hospital provision which has come partly from within the National Health Service (Fasey 1994, Murphy 1994) and partly from the growing recognition among other service providers of the need to provide good quality daycare for people with dementia in as normal a setting as possible. However, there is insufficient provision of appropriate day centres in many, if not most, regions at present.

**Effectiveness of daycare services – research findings***The caregiver perspective*

It is clear from caregiver reports including those recorded by Levin and colleagues (Levin *et al.* 1989, 1994) that daycare is wanted and greatly appreciated by caregivers, providing a much needed break and ena-

bling them to carry out everyday activities. However, rigorous quantitative research into the effectiveness of daycare services for the caregiver is lacking. Existing studies have focussed mainly on the effectiveness of daycare in relieving psychological stress in the caregiver. In a day hospital study, Gilleard showed that daycare attendance appeared to reduce the level of psychological stress in relatives of a subgroup of patients but that for many carers, daycare appeared to be introduced too late to have any real impact (Gilleard 1987). Wells and colleagues, in a study of relatives of day centre attenders in Australia, found that daycare attendance appeared to achieve only minor reductions in stress levels (Wells *et al.* 1990). Levin and colleagues failed to show any significant reduction in stress levels in a sample of carers of daycare attenders in three regions in England (Levin *et al.* 1989). These and other studies have methodological limitations which prevent any conclusions being drawn on the effectiveness of daycare for the caregiver (Curran, 1995). Nevertheless, there is little doubt that some carers benefit greatly from daycare services. Questions to be answered from future research include the characteristics and circumstances of carers most likely to benefit and the optimal time for the introduction of daycare.

*The perspective of the person with dementia*

The direct study of the effects of daycare attendance on the person with dementia has been neglected. Existing reports point to improvements in the emotional well-being, social behaviour and cognitive abilities of daycare attenders in up to 53 per cent of cases (Levin *et al.* 1989, 1994, Jones and Munbodd 1982, Wimo *et al.* 1990). In Levin and colleagues' studies, carers, reporting benefits from daycare in 30 to 40 per cent of cases, perceived their relatives as being happier, more relaxed, more confident and talkative and showing more interest in their environment. The full potential of day care in improving the psychological well-being and behaviour of the person with dementia has yet to be examined systematically as these studies all have methodological constraints and any conclusions have to be tentative. Important questions are waiting to be answered on the characteristics of those most likely to benefit and the optimal frequency of attendance. Daycare tends to be introduced late in the course of a dementing illness (Levin *et al.* 1994), too late, perhaps, to have a significant therapeutic effect. Many people receive daycare one or two days a week when more frequent atten-

dance may be required to have a noticeable effect. Many people with dementia attend daycare at more than one site. For some this may limit benefits of attendance by adding to the disorientation of leaving one's own home.

Outcome for the person with dementia has also been examined in terms of the success of daycare in delaying admission to long-term care. Studies carried out to date have been limited in their methodology and no clear answer to this question emerges (Ballinger 1984, Greene and Timbury 1979, Curran, in press).

#### **Components of good quality daycare for people with dementia – an Australian perspective**

A recent welcome addition to the sparse literature on quality of care in daycare settings has been the Lincoln Gerontology Centre Australian study of day centres in Queensland and Victoria States. The study used a multi-method, mainly quantitative approach which included direct observation of the general activities of the day centres, interviews with centre co-ordinators and staff, and the completion of facilities inventories. Fourteen day centres were studied and comprised six dementia-specific and eight generic day centres in a variety of settings both metropolitan and rural. Summarised below are some of the key elements of good quality care as identified in the study (Davison, Kendig *et al.* 1994).

##### *Staff attitudes, communication skills and knowledge of dementia*

Personal qualities of tolerance, sensitivity and good communication skills were identified as the important characteristics of an effective staff member. Formal qualifications were seen as a requirement for the centre co-ordinator only. In some cases, qualifications were considered to be a disadvantage, fostering a clinical and task-orientated approach to work. Nevertheless, training was seen as crucially important in developing specific knowledge and skills. Training was required to provide staff with a clear understanding of the nature of dementia and associated impairments and knowledge on the management of challenging behaviour. The most important aspect of training was considered to be the fostering of a positive attitude towards professional practice with people with dementia.

In the report, the communication approach was identified as the single most important intervention in caring for people with dementia. The skill lay in knowing when to use a particular approach from a repertoire including validation, reality orientation, non-verbal and verbal cueing, demonstration, guiding, mirroring and touch. Knowledge of the life history of the attender and an accurate assessment of the attender's cognitive functioning and behaviour were perceived as important prerequisites to good communication and care.

##### *Group mix and size*

Dementia-specific daycare appeared to meet the needs of people with dementia better than generic daycare. Staff in dementia-specific day centres were better informed about dementia, more skilled in the management of challenging behaviour and more positive about dementia than staff in generic centres. The ideal number of attenders with dementia was seen as ten, larger numbers in either dementia-specific or generic day centre settings causing over-stimulation and contributing to difficult behaviour.

##### *Management and organisational factors*

Staff worked more effectively when they had unambiguous job descriptions and when the line of authority was clear. Having a clear statement of aims, particularly if formulated by the staff as a group, gave a clearer sense of purpose, highlighted areas for staff training and was particularly helpful for the orientation of new members of staff. A minimum of one member of staff or volunteer to five attenders with dementia was recommended although this staffing level will be seen as inadequate by many practitioners in the field. Staff support and opportunities to air grievances were considered to be important for the effective functioning of staff (Davison 1994) and it was recommended that shifts should not be longer than five hours.

##### *Facilities*

Domestic facilities were found to be most responsive to the needs of people with dementia, with a house setting assisting orientation and participation in domestic activities. Church or municipal halls were seen as least conducive to good care because of lack of facilities and a noisy, over-stimulating environment. Accessible toilets, laundry and bathing facilities, a quiet area for attenders to retreat to if over-stimu-

lated or needing to lie down, and furnishings of a domestic style were all seen as important to good care.

#### *Activities*

People with dementia appeared to respond best to individual and small group attention with familiar activities and domestic routines. Successful activities included music, social interaction and reminiscence, meal preparation and gardening. However, activities needed to be individualised and planned in response to personal preferences, interests and capacities. Unsuccessful activities were those which placed unreasonable demands on attenders such as quizzes, crafts, cards and counting games.

#### *Opening times*

Centres which were flexible in their operating hours, for example offering respite in the late evening, at night or at weekends, were more responsive to the needs of carers and attenders with dementia as were day centres offering daycare more than two days a week.

#### **Innovations in daycare**

The needs of people with dementia and their informal caregivers are very varied. A flexible approach to the provision of daycare is desired if services are to begin to meet these needs. Highlighted below are some of the particular problems associated with daycare and some of the approaches employed to overcome them.

#### *Activities*

Larger day centres tend to organise activities in groups with little reference to the preferences of individual attenders. To make activities enjoyable and stimulating to as many attenders as possible an individualised approach is required in the planning stage. This has been achieved at the Holy Corner Tuesday Club in Edinburgh which accommodates eight or nine people with dementia (Goldsmith and Wright 1993). A staff meeting is held once a month and a programme of activities planned for each individual. The individualised approach is enhanced by the high number of trained volunteers present allowing a one-to-one staff-attender ratio.

Other day centres incorporate activities which were habitually carried out by attenders in the past. At Berwickshire Dementia Day Services Day Centre, clients shop for and cook meals for themselves. Other day centres emphasise domestic activities such as ironing, dusting and sweeping in addition to the preparation of meals.

#### *Transport*

One of the perennial problems associated with daycare attendance is the transportation of clients to and from day care services (Levin 1994, Tester 1989d). Most day centres and day hospitals use minibuses and ambulances. Transport problems identified by Tester included limited hours of availability of transport, shortage of specialised vehicles such as tail-lift ambulances and unpredictability of transport arrival times. Variability in the times of arrival and return makes it difficult for carers to plan their day. Long travelling times can be distressing for the client and lead to behaviour disturbance on the bus, travel sickness and rejection of daycare. Some attenders feel stigmatised by having to travel in hospital or day centre vehicles.

Solutions given by Tester included securing an adequate transport budget, a co-ordinated transport system for an area incorporating all the relevant agencies, client groups and venues and the use of volunteer car services and taxis.

The Rosebank day centre in Kilmarnock avoids minibuses altogether by using volunteer drivers with private cars and taxi drivers (Archibald 1992). Use of taxis has allowed more flexibility in the hours of attendance. Because the taxi drivers involved are few in number, they have become familiar with and sensitive to the difficulties of attenders over time. This approach is limited to the more physically fit, however.

The REDS project in Glasgow (Archibald *et al.* 1992), which runs a day centre for up to 18 people with dementia per day, until recently incorporated the bus journey into the activities programme. The escort used the journey for reminiscence work, often focussing on landmarks along the way, and included memory games and songs during the journey.

#### *Daycare as a component of care provided*

Daycare can meet only some of the needs of people with dementia and their carers. Some service providers are now trying to meet these needs in a number of different ways which includes daycare. An example of

good practice in this respect is Rosebank in Kilmarnock. Based in a local authority residential home, it offers four day places a day, four long-term care and four respite residential places as well as a 24-hour staffed phone line (Archibald 1992). Attenders and carers generally find respite admission to a place already familiar to them more acceptable. The Govan dementia project offers day care for up to 11 attenders seven days a week and has an overnight service with workers checking on vulnerable people at home (Ilsley 1992). The day centre also has one bed for crisis care. The REDS project, in addition to day care, offers home support 24 hours a day if necessary and an advice and information service (Archibald *et al.* 1992).

#### *Support of informal caregivers*

Most day centres and day hospitals consider carer support to be among their most important roles (Lardner 1991). Most hold regular carer support groups. Some services have tried to address the needs of carers more directly by offering a 24-hour help line, or providing information and advice on dementia and services available. In Strathclyde Region, the Young People's Project, set up to develop services for younger people with dementia, offers a counselling service to carers throughout the region including carers of day centre attenders.

#### *Caregivers who want to come too*

Established daycare services sometimes discourage informal caregivers from staying with their relative during daycare attendance. Although most caregivers would not wish to accompany their relative, some are unhappy about leaving the person with dementia at the daycare service particularly in the early stages of attendance. Other caregivers wish not so much for daycare as to have somewhere to go as a couple. Central Regional Council Dementia Initiative tries to accommodate such carers by running a drop-in facility in three towns (Central Regional Council 1994). These provide a relaxed cafe environment where people with dementia and their carers are welcome. Carers can meet others in similar situations and can obtain information on other resources. Alternatively, they can use the facility as a means of respite and take a break for a few hours if they wish. The drop-in facility can serve as a gentle introduction to services and pave the way for the acceptance of other supports. Although this service is not daycare as such, in that it does not provide a formal programme of activities for

people with dementia, it illustrates well how other day facilities can have important roles to play in ensuring a comprehensive service. The Dementia Initiative also runs a daycare programme which caregivers are welcome to attend with their relative.

#### *Daycare hours*

A problem highlighted by carers in Levin and colleagues' surveys (Levin *et al.* 1989, 1994) is the rigidity of attendance times offered by many daycare services. Attendance is usually limited to five or six hours between 9am and 5pm, Monday to Friday. A more flexible pattern of attendance is now provided by some day centres, acknowledging that the routines of carers and people with dementia vary, that daycare may be acceptable at some times of the day but not at others and that care at weekends in addition to or instead of weekday attendance may be required. The approach adopted by Rosebank (Archibald 1992) has been to offer daycare in four hourly units up to 11pm. This approach is facilitated by the use of taxis instead of minibuses.

#### *Home-based daycare*

Having a menu of care is now seen as one of the best ways of ensuring that the needs of as many people as possible are accommodated by services on offer. This approach does not have to entail a great deal of extra cost. A recent addition to the menu of care has been the development of daycare based in private family homes. In Central Region in Scotland, daycare is provided in eight private homes each catering for up to six people with dementia (Central Regional Council 1994). The domestic setting enables many attenders to settle in quickly. Because attenders live locally, some walk to the house. The small size of the group facilitates the establishment of friendship and trust. The venture appears to provide good value for money. However, attendance is limited to the physically fit as the private dwellings lack facilities for physically disabled people. It also has the disadvantage of relying on the one or two volunteers who provide the service in each house with the possibility of cancellation if the volunteers cannot attend on the day.

#### *Differing gender needs*

Service providers are often aware that the needs of male and female attenders have to be addressed in different ways. While domestic activities and informal chat may suit many women, men tend to prefer

activities related to their former employment or hobbies. Alzheimer Scotland Action on Dementia runs daycare exclusively for a group of younger men with dementia one day a week in a community centre in Kilmarnock, Scotland. This appears to meet the needs of attenders very well. The attenders themselves decide on most activities and favour pool, darts, dominoes, indoor bowls, cards and table tennis either in the community centre or in local facilities. Most of the staff are also male.

#### *Younger people with dementia*

Most people who develop dementia at an early age, i.e. in their early sixties or before, do not fit easily into available daycare services which cater mainly for elderly adults. Lardner (1991) in a recent survey of specialist day care services for people with dementia in Scotland has noted the dearth of services specifically for people with early onset dementia. Alzheimer Scotland Action on Dementia, which runs day centres for people with dementia throughout Scotland, addresses the problem in a number of ways. Some day centres allocate one day a week specifically for younger people with dementia. In Strathclyde Region, younger people usually attend on days allocated to those in the early stages of dementia of whatever age. In this region, however, sitter services are the more usual source of respite for carers of younger people in the early stages of dementia and are seen as more acceptable to both carers and those with dementia.

#### **Implications for policy and practice**

The potential benefits of daycare attendance seem clear from our understanding of the nature of dementia and of the difficulties faced by caregivers. Caregiver accounts emphasise the importance of day care services for them and many people with dementia appear to derive great benefit from attendance.

Further research, both quantitative and qualitative, is required to elucidate for practitioners and policy makers the full benefits of daycare for the person with dementia. Early introduction of good quality daycare could potentially have marked effects on the psychological well-being and cognitive state of the attender, improving their level of independence. The frequency of daycare attendance may be crucial in determining the level of response. The characteristics of those most

likely to respond need to be determined. As there is under-provision of daycare services for people with dementia at present and as most people with dementia commence attendance relatively late in the course of their illness (Levin *et al.* 1994), evidence of effectiveness in the earlier stages should be followed by the development of more services to cater for people with less advanced dementia.

Similarly, much remains to be learned about the benefits of day care for the informal caregiver. Daycare services, to be as effective as possible in relieving the burden of care, should be introduced in response to careful needs assessment and in the context of a tailor-made package of care. Daycare will be an inappropriate form of respite for some carers. For example, where a high level of assistance with personal care is required, preparing the person with dementia for daycare may increase workload rather than reduce it (Berry *et al.* 1991) and a sitting service may be more relevant. Previous studies have tended to evaluate day care in isolation, addressing neither the issue of needs assessment nor of other services received (Curran, 1995). There is a need for research to examine services in this context.

For the service provider, a flexible approach to service provision is crucial. Activities should be individualised. The environment should be as homely as possible. Staff need to be clear about their roles and the objectives of the centre. Training in understanding the nature of dementia, an accurate assessment of each attender's cognitive functioning and behaviour and a knowledge of their life history are essential. The rights of attenders to dignity, privacy and respect should be emphasised. Day centres offering extended hours can serve attenders and carers best. Staff should liaise with other service providers to ensure good care management.

Evaluation should occur at day centre level and include the views of staff, caregiver and attender. Eliciting the views of attenders with dementia has not usually occurred in the past but is increasingly recognised as important (Davison, Jordan *et al.* 1994). Staff turnover and sickness rates are important pointers to the quality of the working environment for staff. In-house evaluation through the analysis of critical incidents has been advocated by Davison and colleagues (Davison, Jordan *et al.* 1994). Occasional evaluation by an outside agency is likely to be helpful.

*Caring for People* (1989) has laid out the principles guiding service providers of community care services. If the rhetoric is to be reality,



sufficient resources will have to be allocated to the development of good quality services for people with dementia living at home. Day care services should be provided in response to the assessed need of the person with dementia and the informal caregiver and as part of a tailor-made package of care with due attention to the cost effectiveness of services provided. Co-ordination in the planning of services at a local level is required to avoid gaps in provision and the duplication of services. Flexibility and imagination are required in developing appropriate services in a local context. This includes addressing the needs of minority groups such as younger people with dementia and those from non-English speaking backgrounds.

Day hospitals in old age psychiatry have important assessment and rehabilitative roles but their role in the longer term support of those with dementia needs to be clarified. Because of the staff skill mix and hospital resources available, day hospitals appear to be best placed to continue with the longer term support of those with more severe behavioural problems, mood disturbance, very high levels of dependency or complex physical problems in addition to dementia.

Small dementia-specific day centres in domestic settings with empathic, trained staff and using a normalising approach, appear best placed to provide good quality day care for many people with dementia. Skilled staff have much to offer in the training of other service providers in the area. However, such care does not require a specific centre but can be provided in private homes and could therefore be developed on a wide scale in rural as well as urban areas. Generic day centres can also cater for people with dementia, either on separate days, or by addressing their particular needs on days of mixed attendance through the organisation of separate groups or the provision of high levels of suitably trained staff. As the needs of people with dementia and their informal caregivers are so varied it is important to have a range of services to choose from, although services ought to be defined by the characteristics of the locality and will inevitably be limited by financial constraints.

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## Evaluating Respite Services

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We aim in this chapter to contribute to the growing debate on how to measure the achievements of community services, using our research on respite care for the purpose (Levin, Moriarty and Gorbach 1994). In the UK, interest in this question has been stimulated by the major changes in the arrangements for social care and the need to assess the impact of the new approaches to service delivery on service users and their family carers (Secretaries of State 1989, National Health Service and Community Care Act 1990).

### The aims of social and health care reforms

The overarching aim of these reforms is to enable people to have their needs for care met in their own homes, wherever possible. The policy guidance on their introduction explicitly recognises that family members play a major part in community care, laying upon statutory authorities a responsibility to do all they can to assist and support carers (Department of Health 1990). The provision of such assistance is supported by members of the public, professionals and carers' organisations. There is less agreement, however, about the aims, levels and targeting of support services and the criteria to be used in assessing their effectiveness.

A lack of clarity about aims seems most pronounced when service users have chronic, progressive and unpredictable illnesses such as Alzheimer's Disease and other forms of dementia. Research has shown that the vast majority of people with moderate or severe dementia living at home are cared for by a person in the same household, that one member of the family typically gives far more help with personal care than anyone else and that caring for a person with dementia is