S | P | R | U

MEASURING PERSONAL SOCIAL SERVICES OUTCOMES: SERVICES FOR CARERS

Paper prepared to support research led by the Personal Social Services Research Unit on developing a methodology to understand and measure the outputs of personal social services

Michael Hirst

DHP 2044 November 2004

THE UNIVERSITY *of* York

Measuring Personal Social Services Outputs: Services for carers

These notes aim to define and identify services to unpaid carers that are funded wholly or partly by councils with social services responsibilities. They draw largely on policy and practice guidance for implementing the Carers and Disabled Children (CDC) Act 2000 (Department of Health, 2001a, b, c), and guidance on use of the Carers Grant.[1] Sources of information on services to carers, including data collected in the Referrals, Assessments and Packages of Care (RAP) return for the carers' performance indicator, are also reviewed. SPRU research on the outcomes that carers see as desirable is briefly described alongside suggestions for revising the OPUS schema proposed by PSSRU. A preliminary attempt is then made to map services for carers onto the OPUS domains. Finally, research needs and priorities for measuring social services outputs and productivity in relation to carers are outlined.

Defining services for carers

Under the CDC Act 2000, local councils can supply or commission services to carers who provide or intend to provide a substantial amount of care on a regular basis. Services to carers are broadly defined as services that address the carer's own support needs, as distinct from community care services that meet the care needs of the person cared for. More specifically, services to carers may be provided following assessment of the carer's eligibility for support, and must meet one of two criteria:

- That they will support and sustain the carer in their caring role.
- That they will help maintain the carer's own health and well-being.

In most cases, services to carers are supplied direct to carers; however, a carers' service may take the form of a community care service delivered to the cared for person where the person cared for has refused an assessment of their own needs or any support other than that provided by the carer. In these circumstances, the carer's support needs may be met if the cared for person accepts a service that helps the person who cares for them. For example, a cared for person who has refused an assessment may agree to the provision of a day service or a non-intimate sitting service to give their carer a break.

Local councils can charge carers for the services provided to them. Local councils also have the power to make direct payments to carers to purchase services to meet their own assessed needs.

---

1. Published on the Department of Health website.

Identifying services to carers
Four kinds of services to carers are distinguished in the guidance to local councils: services that provide breaks to carers, specific carers' services, information and advice, and other services for the cared for person. Each is discussed in turn:

Services that provide breaks for carers
Breaks services are about carers having time for themselves. Respite services provided to a cared-for person as a community care service are considered to be a breaks service where they actually give the carer a break from direct responsibility of supervising or caring for that person. Services provided in an emergency, such as when a carer is hospitalised, or simply to allow the carer to visit the doctor or dentist, are not regarded as a breaks service but as a core element of supporting the cared for person and carer.

Breaks services come in many different forms, and offer carers respite for spells of varying frequency and duration. They can include day care or overnight care, and may be provided in the cared for person's home, in a host family's home, or in a communal or institutional setting (Arksey *et al.*, 2004). These variations clearly have implications for measuring, costing and valuing PSS outputs; however, as we shall observe, different kinds of breaks services are not currently specified in official returns of PSS provision. Breaks or respite services can also be delivered in different ways, which may further complicate the measurement of outputs. As well as direct provision, councils can fund voluntary organisations to provide breaks for carers; councils can also provide vouchers to carers to access breaks services.

Specific carers' services
Carers' services are not defined as such and may take any form; unlike breaks services however, they are delivered direct to the carer. Local councils are expected to be flexible and innovative in meeting the assessed needs of carers who are eligible for support. According to policy guidance, the key to identifying what might be an appropriate service for carers depends on whether it is expected to have a positive impact in terms of supporting carers in their caring role or helping them maintain their own health and well-being. Whether that is the case in practice will obviously be a matter for empirical investigation. Moreover, the focus on these two domains does not preclude carers' services having a positive impact in other outcome domains that carers value (see further below).

Consequently, services for carers can be extremely varied; examples include:
1)   Counselling, emotional support.
2)   Moving and handling classes.
3)   Training in coping skills, for example coping with the difficulties associated with dementia, challenging behaviour, or stroke rehabilitation.
4)   Help with caring tasks during the day or night.

5)   Instruction or education about the cared for person's medical condition, care needs, treatment and medication.
6)   Help with household tasks.
7)   A short holiday for carers to enable them to have time to themselves.
8)   Complementary therapies to relieve stress.
9)   Help with gardening.
10) Provision of a mobile telephone.
11) An alarm system in the home.
12) Help with taxi fares or driving lessons.
13) Courses for carers to take up new learning, training, work or volunteering opportunities, including help with confidence building and skills.

Some councils have produced an A to Z of local carers' services, which might help produce a more comprehensive list.

Information and advice
The provision of information and advice may by a one-off activity (a 'basic service'), or an ongoing commitment to individual carers. According to RAP guidance, a basic service would be defined as providing a 'baseline minimum set of information' that would include:
1)   Social service telephone number for emergencies.
2)   National voluntary sector contact information and local numbers if available.
3)   National financial support telephone number.
4)   General advice on back care, and moving and handling.
5)   Anything else relevant to the individual's circumstances.

To this baseline might be added:
6)   Information about carers' rights under the CDC Act 2000 to assessment and review, and procedure for making complaints. Under the Carers (Equal Opportunities) Act 2004, councils will have a duty from April 2005 to inform carers that they may have a right to an assessment.
7)   Information about direct payment and services for direct payment users (local support group, voluntary organisations with expertise in this area, direct payments support worker, or local centre for independent living, for example), short-term break voucher schemes, and charges for the services provided to carers (and the right to ask for a review of the assessed charge).
8)   Signposting information and internet sites to help carers find key agencies and the services that can support them in their caring role or to maintain their health and well-being, including carers' centres, carers' support groups, and local services providing benefits advice.
9)   Information about education and training opportunities, leisure activities, and support for staying in or taking up paid employment. Following implementation of the Carers (Equal Opportunities) Act 2004 in April 2005, consideration must

be given to the carer's interests and wishes in respect of work, study or leisure during a carer's assessment.

10) Health improvement information, including stress management techniques and coping strategies.

11) Information on the cared for person's medical condition and the effects of treatment.

12) Local forums where carers can contribute to service planning and development.

13) Legislative rights in relation to caring for someone with mental health problems or cognitive impairments.

Other services for the cared for person

The fourth category includes community care services delivered to the cared for person (e.g. help with cleaning and laundry) that are provided primarily to support the carer to care and maintain their own health and well-being. As described above, a carers' service may take the form of a service delivered to the person cared for because the cared for person has refused an assessment or the delivery of services to them in their own right. Advice, information and social work that forms part of the care management process (for the cared for person) might also support carers in their caring roles. Carers' involvement in planning the development and delivery of community care services may itself be construed as a service to carers when accounting for local council funding of administration relating to the carers' plan and consultation with carers.

Although helpful in moving the present agenda forward, this four-fold classification does not fully capture the extremely varied, complex and sometimes ambiguous ways in which carers are supported in the service system; inevitably so, since Twigg and Atkin (1994, p. 11f) have shown that there is no simple way to identify what counts as a service for carers. They have drawn particular attention to the support that carers often receive as a by-product of the services for the cared-for person; they have also highlighted the assumptions and expectations held by service providers about carers that influence the support they receive, and the difficulties of distinguishing service processes, outputs and outcomes (see further below).

RAP data on carers' services

The RAP return for 2004/05 will collect data on the number of carers (of people aged 18 or over) receiving an assessment or review; it will also count, for the first time, the number of carers receiving different types of services following assessment or review. These data will refer to the six-month period from 1 October 2004 to 31 March 2005; thereafter data on carer services activity covering the whole year will be collected. Carers are distinguished according to four age groups in the RAP returns: under 18, 18 to 64, 65 to 74, and 75 years and over. From 2005/06, it is proposed that information about carers' assessments and carers' services would be

differentiated by the client group of the person cared for.[2] Information on carers' ethnicity may also be collected from April 2005.

RAP data on carer assessments and services to carers are discussed here in turn.

Carer assessments and reviews
The RAP return is intended to count the number of carers for whom assessments or reviews were completed during the reporting period. An assessment is defined as the first assessment for a new carer; all subsequent assessments or reassessments are defined as a review. Councils can contract out the assessment process to other organisations: these assessments are included in the RAP return provided the council has funded the process and checked each individual assessment carried out by another organisation.

Carers may be assessed in conjunction with the assessment of the cared for person for community care services, or separately. Joint and separate carer assessments are differentiated in the RAP return. The number of carers declining an assessment is also recorded.

Although carers' assessments or reviews are not in themselves a service to carers, they form a substantial part of PSS output. Moreover, the assessment process itself can be important and beneficial to carers even where services or direct payments for the carer are restricted or do not follow. According to Banks and Cheeseman (1998), positive outcomes for carers of having an assessment include:
- Respect for and recognition of their caring role.
- Peace of mind from knowing how to make contact in the future.
- A chance to talk through the issues and consider their own needs.
- Information about other support such as local carers' groups and statutory and voluntary services.
- A sense of shared responsibility and acknowledgement of the carer's expertise.
- Increased confidence to take up services.

By counting the number of carers receiving an assessment or review, the RAP return provides an indication of PSS activity that can produce such outcomes. Moreover, the distinction between joint and separate assessments might, with further examination, become a proxy measure of their relative value or contribution to carer support. Conducting an assessment away from the cared for person, for example, would give the carer time with the assessor to talk in confidence about the impact of their caring role, which in some care situations may be valued more highly than a joint assessment.

---

2. Five client groups will be distinguished: Physical disability, frailty and sensory impairment; Mental health; Learning disability; Substance misuse; and Other vulnerable people.

Further investigation would also be required to determine how far, and in what ways, the number of carers receiving assessments or reviews accounts for PSS activity or resources devoted to carer assessment. RAP data are based on the number of carers, not the number of assessments or reviews. Thus, carers are counted only once even if they were assessed or reviewed two or more times during the period covered by the RAP return. This may be the case when there are rapid changes in the care-giving situation, including marked fluctuations or deteriorations in the health of the person receiving care. Given the potential benefits of assessment, there is an argument for counting the number of carers' assessments rather than relying solely on the number of carers assessed. Counting the number of assessments would also provide a more accurate indicator of the amount of PSS resources devoted to carer assessment. In addition, the unit costs of carers' assessments will depend on the nature and circumstances of the care situations that are identified: these may vary in complexity over time, and influence the measurement of productivity.

Services to carers

The RAP return also counts the number of carers receiving services that were identified as being needed following a carer's assessment or review during the reporting period. Services to the carer provided directly by a local council or an organisation on its behalf are recorded. However, the RAP return would not necessarily reflect councils' grant aid funding to carers' organisations (for example, the Princess Royal Trust for Carers to run a local carers' centre) in that carers may benefit from such provision whether they were assessed or not during the reporting period.[3]

The first three types of services for carers described above are covered in the RAP return: services providing breaks for carers, other specific carers' services, and information and advice. The fourth category of service to carers, community care services delivered to the cared for person that are provided primarily to support the carer, may be included in future returns.

Evaluating RAP data on carers

On the face of it, the RAP data on carers' assessments and carers' services provide useful information on PSS output; however, a number of limitations are apparent:

- Breaks services and other specific carers' services are combined in the RAP return, so there is no way of knowing how many carers are receiving either or both kinds of service. Moreover, the different types of breaks and other carers' services are not specified in the RAP returns: there is no precise information about the individual services or service packages that carers actually receive. As noted above, services for carers encompass a wide range of quite disparate provision, with varying impacts on carers' outcomes and requiring varying levels

---

3. Considering the impact of grant aid funding would be relevant where it is counted as PSS expenditure.

of resources. Until the RAP return is adapted to reflect more accurately the amount and diversity of provision for carers, it will be necessary to supplement the information it provides with survey data on the services that representative groups of carers actually receive.

- The provision of information and advice is recorded only if neither a breaks service, nor any other specific carers' service, is provided. It may be reasonable to assume that the provision of information and advice always accompanies a carers' assessment, in which case every carer counted on the RAP return could be assumed to have received information and advice, perhaps even those who are recorded as refusing an assessment. Research may be required to establish how far this is the case.

- In the absence of a more refined RAP return, surveys of carers will also be required to establish the nature, extent and value of the information and advice given to carers, and to find out how such provision is organised and delivered (whether a passive or more active approach is adopted, for example).

- If a carer is assessed or reviewed more than once during the period covered by the RAP return, only services provided following the most recent assessment or review are recorded. Services discontinued following reassessment or review would not be recorded even if they had been received earlier during the reporting period. Moreover, the RAP return covers provision put in place only for those carers who were assessed or reviewed during the reporting period.[4] Services that continue to be received by carers following assessment or review in an earlier period would not be counted.

In summary, RAP returns do not provide a comprehensive picture of the volume and types of service activity, including assessment, that are funded by PSS expenditure and received by carers during a reporting year. Alternative approaches to collecting information on carers in the RAP returns are currently under consideration, including records at an individual rather than aggregate level, which may provide fuller details and allow more flexible use of the data. In the meantime, research will be required to measure and monitor the services provided or funded by councils to carers. As the range and scope of carers' services are developing rapidly in response to recent legislation, guidance and central funding, such research would need to be repeated periodically.

Other official data on carer's services
Form HH1 is completed once a year by social services to provide information on home help and home care services for adults during a sample week in September . Amongst other services, it covers respite care provided in the client's home to enable the carer to take a break from the tasks involved in caring. However, the statistics simply record the total number of weekly contact hours for all domiciliary services

---

4. Where an assessment or review occurs near the end of a reporting period and services are not yet delivered, the RAP return will count the carers in this situation and record the services that were agreed with them.

taken together, and do not differentiate respite provision. Moreover, respite provided away from the cared for person's home would not be recorded.

The Beacons Council Scheme theme for 2004/05 'Supporting Carers' aims to promote the development of services for carers including through partnership arrangements, and encourage carer involvement in strategic development and service planning. These activities may generate new information about the services that carers use.

Local authority user satisfaction surveys may provide insights into carers' views and experiences of service organisation and delivery. However, the judgement of those in the Department of Health who were involved in developing proposals for the new carers' performance indicator is that existing information systems are unable to gather sufficiently high quality data on carer satisfaction.

Other sources of data on carers' services
Several nationally representative surveys identify carers and collect data on their circumstances, including their contact with or receipt of services. The most comprehensive source of data on carers and services is the General Household Survey (GHS), which has included a questionnaire module for carers every five years or so since 1985 (Maher and Green, 2002; Singleton *et al.*, 2002). Other surveys that provide more limited coverage of carers or services than the GHS include the British Household Panel Survey and the Family Resources Survey, both conducted annually, and the English Longitudinal Study of Ageing, which is repeated every two years.

While these surveys are useful for mapping service utilisation and formal support to carers, several weaknesses limit their contribution to measuring PSS outputs:
- It is rarely known whether the services received by carers, or the cared for person, were provided specifically to support the carer's caring role.
- Where carers are known to receive a specific carers' service (for example, a breaks service, training, information and advice on caregiving), it is not known whether the service was funded wholly or partly by social services. Indeed, carers may not always know whether the service they received, or their contact with a practitioner, was provided by social services or another agency.
- The period when services were received by carers may be uncertain, although it may be reasonable to assume that in most cases this had been in the past year.
- The amount of each service that carers have received is not recorded.

Outcome domains for carers
Official guidance for the CDC Act 2000 and the Carers Grant concentrate on two outcome domains for carers: helping carers in their caring role; and helping carers maintain their own health and well-being. Carer assessments are conducted in part to determine if the carer's support needs in these two domains can be met by

services provided or purchased by a council with social services responsibilities. The Carers (Equal Opportunities) Act 2004 has extended the range of outcomes to be considered during carers' assessments to include the carer's needs in relation to paid employment, education, training, or any leisure activity.

Research conducted at SPRU identified a range of particular outcomes that carers themselves value, from which a typology of carers' outcomes was developed (Nicholas, 2000, 2001, 2003). The value of this typology is that it fleshes out the scope and content of the two domains that are the focus of legislation and guidance. It also provides a framework for evaluating the applicability of the OPUS schema for representing the experiences of carers. An important question then is the extent to which the SPRU work on carers' outcomes maps onto the OPUS domains.

From the outset, the SPRU research was carried out to underpin efforts to introduce an outcomes focus into social care practice and produce practice tools to facilitate that process (Ball *et al.*, 2004). The typology describing outcomes for carers was subsequently incorporated in the practitioner's guide to carers' assessments under the CDC Act 2000 to inform the process of assessment and review. However, the SPRU research did not aim to develop and test outcome measures in a quantitative framework, and the outcomes identified were described and presented as an aide-mémoire or prompt to the assessor, rather than as a comprehensive or exclusive list.

Four distinct but interrelated dimensions of outcomes were identified as important to carers: quality of life for the cared for person; quality of life for the carer; recognition and support in the caring role; and service process outcomes. Each is described in turn below.

The first dimension, achieving quality of life for the cared for person, includes:
• Personal cleanliness and comfort.
• Maximum independence and mobility.
• Personal safety and security.
• Social contact with others (apart from the carer).
• Meaningful activity/stimulation.
• Maintain dignity and morale.

This dimension underlines the observation that what carers most want is good quality services for the cared for person (Department of Health, 2000; Parker & Clarke, 2002). In large measure, good quality community care services for the cared for person would enable most carers to sustain their caring role alongside their other roles and responsibilities, and consequently affect carers' outcomes indirectly (Twigg and Atkin, 1994, p. 16). Although the outcomes forming this dimension are mostly captured by the domains already identified in the OPUS schema for users of community care services, the OPUS schema does not currently consider carers'

views on the quality of such provision. Taking account of carers' views and preferences about the quality of services for the cared for person may not require an additional OPUS domain but could have implications for weighting the Role Support domain.

The second dimension, achieving quality of life for the carer, includes:
- Maintaining physical health, fitness and well-being.
- Positive morale, emotional and mental health.
- Peace of mind (freedom from excessive anxiety about the person cared for).
- Freedom to have a life of their own and feel in control (e.g. to work if they choose; pursue own interests and other commitments; maintain friendships).
- Avoid social isolation.
- Positive relationship with the person cared for and managing conflict sensitively.
- Adequate material circumstances and financial security (income and housing).

The OPUS schema probably encompasses many of the outcomes on this dimension. However, the emphasis on maintaining carers' physical and mental health, which is also a priority for carers' legislation and the guidance to support it, indicates that positive health and well-being should be considered an additional domain in the OPUS schema.

Material well-being or financial security for carers might also be considered as an additional OPUS domain, or included within the Role Support domain (see below). Caregiving is often associated with financial stress as a consequence of additional expenditure (e.g. laundry, heating, travel), and loss of income if the carer (and the cared for person) has to relinquish or reduce paid employment (Glendinning, 1992). Financial security for carers has also been identified from a review of the literature as a key outcome for local carer support services (Unell, 1999). The relevance of carers' financial well-being as an outcome of PSS activity stems from the observation that councils can impact directly on carers' financial circumstances by influencing the availability of services or direct payments, their policies on charging, and the provision of benefits advice and advocacy.

The third dimension, recognition and support in the caring role, includes:
- Able to define the limits of the caring role and make informed choices (about level of involvement and nature of caregiving tasks).
- Feeling informed, prepared/confident, skilled/equipped, or trained for the caring task.
- A sense of satisfaction or achievement in caring.
- A sense of shared responsibility, both practically and emotionally, with services including emergency access to help.
- Able to manage the physical and practical tasks of caring.

In practice, the Role Support domain in the OPUS schema should cover all these outcomes. Material well-being and financial security, identified above in the dimension 'quality of life for the carer', could also be included under Role Support. This would reflect the focus of that domain on addressing needs around supporting and sustaining a caring role: in this case, the potentially adverse impact of caring on the carer's material well-being and the financial risks associated with caregiving.

The fourth dimension, service process outcomes, refers to the way in which services are organized and delivered, how care plans are made, and the quality of carers' interaction with practitioners and service providers. This dimension includes:

- Being valued and respected as an individual.
- Recognising carers' needs and expertise.
- Having a say in how a service is provided.
- Achieving a good fit with existing life routines and patterns of caregiving.
- Responsive to changing needs.
- Positive relationship with practitioners and service providers.
- Accessible, non-bureaucratic, and available at the point of need.
- Value for money (in the context of service charges and council tax payments).

How services are delivered is important for both the carer and the cared for person, and may have serious implications if the process leads to refusal of an assessment or service, or the carer has to cope with additional hassle and distress. As Twigg and Atkin (1994, p. 18) have argued: 'central to the experience of carers [is] that the ways in which things are done is part of what is done'.

It may not be possible or appropriate to include service process outcomes as an additional domain in the OPUS schema. Service processes are primarily about enhancing or hindering the achievement of the desired outcomes for the carer's well-being and support for the caring role. Although service processes influence carers' experiences of contact with PSS and the support put in place following assessment or review, they are not a service output as such. Clearly, service processes will inform carers' judgments about the value of the services they and the person they care for receive, and may affect whether they continue to use the services offered. Hence, service processes might be reflected in the extent to which services for carers map onto outcomes for carers. Service process outcomes may therefore have implications for weighting the Role Support domain.

Twigg and Atkin (1994) have proposed four models to describe the various ways in which service providers relate to carers: carers as resources, as co-workers, as clients, and the superceded carer. Although not seen as mutually exclusive categories, these models help to explain how carers experience the service responses to them and might provide a framework for evaluating those responses and measuring carers' views.

Mapping carers' services onto outcomes for carers

As indicated above, all services to carers funded wholly or partly by councils following a carer's assessment are intended to produce benefits in one or both of two outcome domains: supporting carers in their caring role; and helping them maintain their own health and well-being. Research evidence supports the desired role for PSS outputs. Breaks services and some other specific carers' services, as well as the provision of information and advice, have been shown to produce positive outcomes for carers in these domains, although much more needs to be known about what works for carers, which carers are most likely to benefit, under what circumstances, and for how long (e.g. Arksey *et al.*, 2004; Brodaty and Gresham, 1989; Graham *et al.*, 1997; Kalra *et al.*, 2004; Knapp *et al.*, 2000; Knight *et al.*, 1993; Pickard, 2004). Qualitative evidence from discussions with carers indicates that the assessment process also maps onto the two key domains identified in policy and practice guidance (Banks and Cheeseman, 1998; Nicholas, 2003).

Accordingly, breaks services and other specific carers' services, as well as carers' assessments, should map directly onto either the OPUS Role Support domain, or the proposed additional domain Positive Health, or both. The provision of information and advice to carers also maps onto the Role Support domain. It may be the case that breaks services, other specific carers' services, and information and advice, produce benefits for carers in other OPUS domains; for example, Social participation and involvement, Control over daily life, Environmental cleanliness and order (housework), and Occupation and mental stimulation (including paid employment). As already noted, the Carers (Equal Opportunities) Act 2004 intends that positive outcomes be achieved for carers across a range of outcome domains covering employment, education, training, and leisure activities. However, it is difficult to be more precise about the role of individual carer services because not enough is known about what is provided and why, or their impact on outcomes for carers.

Research needs and priorities

- The measurement of PSS outputs in relation to services for carers is not straightforward and a common system that covers the diversity of carer provision may be elusive. While number of hours or days per year may be an appropriate way of measuring the volume of breaks services or respite for carers, it is far from clear how service activity and volume associated with carers' assessments, other specific carers' services, and the provision of information and advice, can be adequately measured.
- Little is known about the individual services and service packages provided or funded by councils for carers, and how these map on to the outcomes that carers want. Although it is possible to list the services that carers might receive, the detail of what is actually provided, and the extent to which that produces positive outcomes for carers, can vary enormously. Thus, Arksey *et al.* (2004) found it necessary to distinguish between different forms of respite care for people with dementia when evaluating the impact on carers' well-being.

Information and advice covers an enormous range of provision from leaflets to individually tailored sessions. Training for carers may encompass instruction in basic nursing skills, prevention, and management options, knowledge of prognosis, treatment and medication, facilitating daily living activities, mobility and communication, and use of special aids and adaptations. Differentiating services to carers may help to understand their impact on outcomes, especially if the pattern or composition of provision changes over time.

- Currently available information (in RAP returns and other sources) on the volume, pattern and delivery of PSS received by carers is limited and inadequate. Specially designed surveys, repeated at intervals, will be required to fill these information gaps.

- No research has been conducted to ascertain carers' preferences for, or valuations of, the outcomes they desire, or how these vary across the carer population, between younger or older carers, carers in rural or urban areas, carers looking after frail elderly parents, disabled or chronically ill spouses or children, and carers in minority ethnic communities. Nicholas (2001) has identified aspects of service process, which provide pointers to how carers might be asked assess the quality of the support they receive. Good practice guides for checking the quality standards of local carer support services might also be used to develop a protocol for ascertaining carers' views and opinions about services and service outcomes (Blunden, 2002; Department of Health, 2000).

- As far as is known, no research has evaluated the capacity of carers to benefit from service support in each of the OPUS domains. However, there are some indications in the research literature. Analysis of data on carers from the General Household Survey and the British Household Panel Survey has identified key aspects of the care situation that, individually or together, seem to account for many of the apparent differences in the impact of caring on carers' health, employment and financial circumstances (Arber and Ginn, 1995; Carmichael and Charles, 1998, 2003; Glendinning, 1992; Hirst, 2004; Parker, 1992; Parker and Lawton, 1994; Spiess and Schneider, 2003). These key aspects include: locus of care, that is whether the carer lives in the same household as the cared for person or elsewhere; types of care tasks, drawing an important distinction between personal and/or physical care and other types of practical help; level of responsibility in terms of sole/main, joint or peripheral responsibility for the cared for person; and level of involvement in terms on the number of hours caring per week. For example, capacity to benefit may increase progressively with the number of hours devoted to caregiving because level of involvement is significantly associated with risk to carers' psychological well-being as well as being a useful indicator of costs and opportunity costs to the carer (for example, in terms of reduced participation in paid employment and social activities, and financial strain). However, the Department of Health is anxious to avoid defining levels of caregiving according to the number of care hours provided, and further research may be required to determine the

combination of factors that best distinguish between care situations and carers' capacity to benefit. Moreover, carers are a diverse group of people and other important factors – notably gender – would need to be taken into account when forming judgements about carers' capacity to benefit.

References

Arber, S. and Ginn, J. (1995) Gender differences in the relationship between paid employment and informal care, *Work, Employment & Society*, 9, 445-71.

Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Weatherly, H., Hare, P., Newbronner, E. and Baldwin, S. (2004) *Review of Respite Services and Short-Term Breaks for Carers for People with Dementia*, Social Policy Research Unit, University of York, York.

Ball, S., Mudd, J., Oxley, M., Pinnock, M., Qureshi, H. and Nicholas, E. (2004) Make outcomes your big idea: Using outcomes to refocus social care practice and information, *Journal of Integrated Care*, 12, 13-19.

Banks, P. and Cheeseman, C. (1998) *Taking Action to Support Carers: A carers impact guide for commissioners and managers*, King's Fund, London.

Blunden, R. (2002) *How Good is Your Service to Carers? A Guide to Checking Quality Standards for Local Carer Support Service*, King's Fund, London.

Brodaty, H. and Gresham, M. (1989) Effect of a training programme to reduce stress in carers of patients with dementia, *British Medical Journal*, 299, 1375-79.

Carmichael, F. and Charles, S. (1998) The labour market costs of community care, *Journal of Health Economics*, 17, 747-65.

Carmichael, F. and Charles, S. (2003) The opportunity costs of informal care: Does gender matter?, *Journal of Health Economics*, 22, 781-803.

Department of Health (2000) *Quality Standards for Local Carer Support Services*, Department of Health, London.

Department of Health (2001a) *Carers and Disabled Children Act 2000. Policy Guidance*, Department of Health, London.

Department of Health (2001b) *Carers and Disabled Children Act 2000. Practice Guidance*, Department of Health, London.

Department of Health (2001c) *A Practitioner's Guide to Carers' Assessment under the Carers and Disabled Children Act 2000*, Department of Health, London.

Glendinning, C. (1992) *The Costs of Informal Care: Looking inside the household*, HMSO, London.

Graham, C., Ballard, C. and Sham, P. (1997) Carers' knowledge of dementia, their coping strategies and morbidity, *International Journal of Geriatric Psychiatry*, 12, 931-36.

Hirst, M. (2004) *Hearts & Minds. The Health Effects of Caring*, Carers Scotland, Glasgow.

Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M. and Donaldson, N. (2004) Training carers of stroke patients: randomised controlled trial, *British Medical Journal*, 328, 1099-1101.

Knapp, P., Young, J., House, A. and Forster, A. (2000) Non-drug strategies to resolve psycho-social difficulties after stroke, *Age & Ageing*, 29, 23-30.

Knight, B., Lutzky, S. and Macofsky-Urban, F. (1993) A meta-analytic review of interventions for caregiver distress: Recommendation for future research, *The Gerontologist*, 33, 240-48.

Maher, J. and Green, H. (2002) *Carers 2000*, The Stationery Office, London.

Nicholas, E. (2000) Implementing an outcomes approach to carer assessment and review, *Research Works*, Social Policy Research Unit, University of York, York.

Nicholas, E. (2001) Implementing an outcomes approach in carer assessment and review, pp. 65-117 in Qureshi, H. (ed.), *Outcomes in Social Care Practice*, Outcomes in Community Care Practice, No. 7, Social Policy Research Unit, University of York, York.

Nicholas, E. (2003) An outcomes focus in carer assessment and review: Value and challenge, *British Journal of Social Work*, 33, 31-47.

Parker, G. (1992) Counting care: Numbers and types of carers, pp. 6-29 in Twigg, J. (ed.), *Carers: Research and Practice*, HMSO, London.

Parker, G. and Clarke, H. (2002) Making the ends meet: Do carers and disabled people have a common agenda?, *Policy & Politics*, 30, 347-59.

Parker, G. and Lawton, D. (1994) *Different Types of Care, Different Types of Carer*, HMSO, London.

Pickard, L. (2004) *The Effectiveness and Cost-effectiveness of Support and Services to Informal Carers of Older People*, Audit Commission, London.

Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R. and Meltzer, H. (2002) *Mental Health of Carers*, The Stationery Office, London.

Spiess, C. and Schneider, A. (2003) Interactions between caregiving and paid work hours among European midlife women, 1994 to 1996, *Ageing & Society*, 23, 41-68.

Twigg, J. and Atkin, K.(1994) *Carers Perceived: Policy and practice in informal care*, Open University Press, Buckingham.

Unell, J. (1999) *Quality Local Carer Support Services*, King's Fund, London.