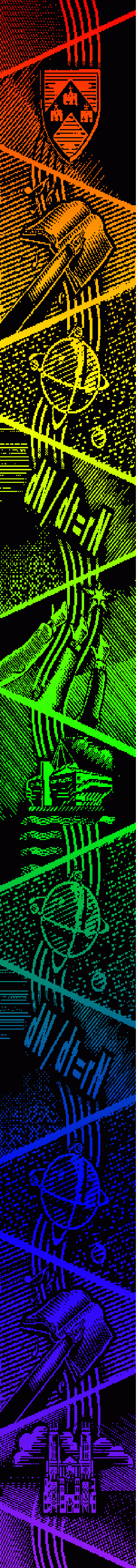

S P R U
Social Policy Research Unit

Understanding and Measuring Personal Social Services Outputs Relating to Disabled Adults and Carers

Contributions to research led by the Personal Social Services Research Unit, University of Kent on Methods for measuring personal social services outputs and productivity

Caroline Glendinning
Michael Hirst
Jennifer Harris

DHP 2093 06.05

The University of York

ISBN 1871713137

A CIP catalogue record for this report is available from the British Library.

Further copies of this report or any other Social Policy Research Unit publication can be freely obtained by visiting our website:

www.york.ac.uk/spru

Paper copies can be obtained from:

The Publications Office
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

Contents

S|P|R|U

Paper 1

RESEARCH TO DEVELOP NEW APPROACHES TO MEASURING AND UNDERSTANDING SOCIAL SERVICES OUTPUTS AND PRODUCTIVITY: SOME CONCEPTUAL ISSUES

Caroline Glendinning

DHP 2053 - March 2005

THE UNIVERSITY *of York*

Research to develop new approaches to measuring and understanding social services outputs and productivity: Some conceptual issues

We have met with the team from the Centre for Health Economics, University of York, who are involved with NIESR in a parallel study to develop measures of NHS outputs and productivity and have discussed with them some of the issues involved in developing measures of social services productivity. The following note draws on the experiences of SPRU's research programme on social care outcomes and raises some questions which we think need to be taken into account in developing measures of PSS output and productivity.

The SPRU Outcomes programme

The DH-commissioned programme of research in SPRU over the past seven years has focused on the outcomes of social care for different groups of service users: working age disabled adults; frail older people; carers; and severely disabled children and their families. Projects have:

- Explored with service users the concept of social care 'outcomes' and defined those dimensions of outcomes that service users value and aspire to achieve;
- Examined a variety of ways in which information about desired service outcomes can be routinely communicated to service providers;
- Investigated different strategies for introducing outcome-related approaches into assessment, review and care planning activities.

The first of these areas of research – the conceptualisation of outcomes – has particular relevance for the proposed research on PSS productivity.

Dimensions of outcomes and their relationships to outputs

Extensive research at SPRU with a range of PSS user groups has identified the following dimensions of social care outcomes:

- Outcomes involving change – for example, improving self-confidence, self-care skills or the accessibility of the physical environment.
- Outcomes that maintain quality of life (or slow down in deterioration in quality of life) – for example, sustaining desired levels of personal comfort, social interaction and control over daily routines.
- Outcomes that are intrinsically associated with the **processes** of receiving services – feeling valued, respected and confident that individual needs and preferences are recognised.

This typology has a number of implications – in particular for the use of output measures as proxy outcome indicators:

- A very high proportion of PSS interventions and activities are aimed at maintenance, rather than change – but there is no evidence about the empirical balance between these two types of activity, and no normative debate about what the correct balance **should** be. Thus an approach to measuring outcomes that aims simply to detect improvements is on its own inadequate; the achievements of PSS may be substantially underestimated if the implicit model of outcome assumes an expectation of detecting improvements. The important question, therefore, is the counterfactual of what would have happened **without** the maintenance-oriented social care intervention.
- Even change-related outcomes may lack an appropriate baseline (or the baseline may be hypothetical) – as in the example of a previously independent older person receiving rehabilitation after a major stroke.
- Most importantly, any focus on activity and outputs risks ignoring crucial process-related outcomes. For the vulnerable groups of people who constitute the focus of PSS activities, process-related outcomes cannot be ignored, as they are critically important in contributing to overall outcomes. For example, an approach to measuring the productivity of home care services that takes into account only activity and outputs (hours of services provided, numbers of people supported) risks incentivising the quick completion of tasks for the maximum number of clients. It ignores the social interaction, the opportunities to exercise choice and control over how tasks are completed, and the (slower) enabling approaches that clients value as constituting high-quality services (and that are also more likely to lead to desired outcomes).

Underpinning this last point is the crucial distinction between outputs and outcomes. Outputs – service interventions and activities – may only partially contribute to desired outcomes. In the PSS context, the relationship between outputs and outcomes is arguably much more tenuous than in health care, where it may be assumed with a fairly high degree of certainty that a specific output or activity (for example hip replacement or cataract surgery) will lead to beneficial outcomes (improved mobility, reduced pain, improved vision) for patients.

In contrast, in PSS, a focus upon activities and outputs may actually reduce the chances of achieving desired outcomes. A classic example would be the reduction of risk and the provision of care in ways that reduce independence and create dependency and institutionalisation. Similar arguments currently arise in relation to the provision of personal care in ways that are incompatible with ‘enablement’ and rehabilitation goals.

A major risk of measuring productivity through measures of activities or outputs, therefore, is that these – rather than desired outcomes - become the focus of evaluation and performance management. The wrong behaviours and activities are incentivised; outcomes are distorted; and productivity measures become counter-productive.

Social care is co-produced by services and users together

In contrast to health care, social care can be thought of as being co-produced. A medical model, in which a given set of signs and symptoms prescribe a routine ‘treatment’, is inappropriate. Social care assessment and review processes aim to identify the **individual** circumstances, needs and risks to which potential users are exposed. The thrust of policies for adults and older people over the past two decades has been to enable PSS to deliver individualised responses to those needs. To a far greater extent than in health care, therefore, users contribute to the specification of needs and the individualised package of services that are to be delivered in response through mechanisms such as care management. To the extent that those service activities are used in measurements of output and productivity, they will reflect substantial elements of user choice and preference.

Moreover, users themselves play a crucial role in the production of PSS outputs and outcomes. PSS may provide a paid carer to help with bathing and dressing, but the responses, feelings and valuation of the experience by the user make a critical contribution to the overall output and outcomes of the service. An emphasis on PSS activities alone risks marginalising the contributions of the service user to the overall output and outcomes of an intervention.

Furthermore, users make substantial contributions to the overall production of PSS in a very real material sense, through the fees and charges they pay. This is most significant in relation to residential and nursing home care, where significant numbers of older people pay the full market costs of their care and others make graduated contributions depending on their assets and incomes. Users also contribute to the production of home care, day care and other related services through means-tested charges.

It will be important to disaggregate these user contributions to overall PSS activity.

The role of other agencies in contribution to PSS productivity

Other welfare agencies also contribute to the productivity of PSS as well.

- The boundaries between health and social care are notoriously blurred, particularly in the complex areas of intermediate, continuing and long-term care. The NHS funds continuing care in nursing homes; and contributes to the nursing care provided for self-funded and social services-funded nursing home residents. The productivity of PSS may arguably have been increased by the recent investment of additional NHS resources in short-term intermediate and rehabilitation services; as a result, more older people may require intensive support for a much shorter time than previously, thereby contributing to a greater throughput of clients.
- To the extent that social security benefits (particularly Disability Living Allowance and Attendance Allowance) are taken fully into account in means-

tested assessments for social care service charges, the DWP budget is also, indirectly, contributing to PSS productivity.

- Housing agencies are also major providers of social care support, particularly for older people and people with learning disabilities. Current DH policy is to promote the development of very sheltered housing facilities as an alternative to residential care.

It will be important to disentangle the contributions of these other statutory agencies to overall PSS productivity.

The role of informal carers

The biggest contribution to the overall production of social care undoubtedly comes from informal and family carers. This has two consequences:

- First, global outcome measures (such as well-being, quality of life, or prevention of admission to institutional care) risk blurring the respective contributions of formal PSS and informal care and, as a result, incorrectly attributing to PSS the substantial practical and social support provided by carers.
- Secondly, an increasing amount of PSS activity is directed to the support of carers themselves. In turn, this may make a major contribution to the overall output of social care. This can be conceptualised as an **indirect** output of PSS activity. The challenges of measuring indirect outputs of this kind are considerable. It may of course be possible indirectly to increase PSS productivity by increasing the levels of PSS support to carers. However, there would be potential implications for other government agencies as well, particularly for DWP, if employment-related support and income replacement provision for carers were not also increased.

The role of independent sector provision

Substantial elements of PSS responsibilities are actually delivered by independent sector providers. This is particularly the case with residential care and increasingly the case with home care services as well. Independent sector providers also deliver services to self-funding users. It would be necessary to distinguish between independent sector services provided to the latter group; and those provided under contract to statutory PSS commissioners. The latter could reasonably be included in measures of PSS productivity, to the extent that they reflect patterns of more or less efficient commissioning and contracting.

Practical challenges

It is unlikely that social services departments’ information systems have the capacity to link data on assessments of need, service inputs, outcomes and costs; or to aggregate routine data about outcomes for individuals. Our experiences of supporting the implementation of an outcomes approach in PSS suggests that analyses of individual outcomes may best be undertaken through customised, one-off analyses rather than through routine data collection and analyses.

Although it would be a crude indicator, it is possible that some of the process-related outcomes discussed above might be reflected in user satisfaction surveys conducted by social services departments. However, routine user satisfaction surveys of PSS clients may fail to capture negative views, particularly on the process-related outcomes of PSS activity, if they are seen to be carried out by or on behalf of the PSS provider. Independent surveys would therefore seem to be essential.

S | P | R | U

Paper 2

MEASURING PERSONAL SOCIAL SERVICES OUTCOMES: WORKING AGE DISABLED PEOPLE

Jennifer Harris

DHP 2046 - November 2004

THE UNIVERSITY of York

Measuring Personal Social Services Outcomes: Working age disabled people

Aims of the paper

This paper examines how far the methodology proposed by Netten *et al*., to measure personal social services (PSS) productivity is appropriate for capturing PSS activities and their outcomes in relation to younger (working age) disabled people with predominantly physical and/or sensory impairments. The paper has the following aims:

- To identify any additional outcome domains that reflect the concerns and priorities of younger disabled people that are not reflected in the outcome domains derived from the PSSRU OPUS study.
- To compare the new amalgamated list of outcome domains with a ‘profile of needs/ outcomes’ and ‘profile of interventions’ derived from an examination of the activities undertaken with younger disabled people in one social services department during 2004 (Harris et al forthcoming). This comparison will enable us to identify the relative priorities attached to the various outcome domains by this user group.
- To discuss issues relating to social services activities and outcomes that are important to younger disabled people.

Identifying additional outcome domains that reflect the concerns and priorities of younger disabled people

A comparison of the PSS outcome domains proposed by Netten *et al*., for older people with the outcomes framework (see Appendix 1) developed by Harris *et al.* (forthcoming) shows five overlapping domains. These are:

Harris *et al.* (see Appendix 1)	**Netten *et al.***
Personal hygiene	Personal care/comfort
Safety	Safety
Security	Safety
Desired level of cleanliness of home	Environmental cleanliness and order
	Access to support in parenting role
	Role support

Outcome domains relevant to PSS activities with younger disabled people that are missing from Netten *et al’s*. paper are as follows:

Table 1: Missing outcome domains for younger disabled people

Outcome domain	*Description*
Access to all areas of home	Mobility within home, gaining access to all rooms and garden safely
Access to locality + wider environment	Mobility outside the home, ramps, issues of access to public transport, public buildings and services
Communicative access	Provision of British Sign Language interpreters, Braille, large print, tape, talking books service
Financial security	Welfare rights, access to full benefit entitlements, financial decision making
Emotional well being	'Mental health' and welfare
Access to paid employment as desired	Self explanatory
Access to training	Self explanatory
Access to further/higher education to secure employment	Self explanatory
Access to appropriate training for new skills (e.g. lip reading)	Self explanatory
Access to mainstream leisure activities	Self explanatory
Access to support for personal relationships	Self explanatory
Access to advocacy/peer-support	Support from national and local organisations of disabled people (e.g. DCIL, Shaping Our Lives)
Citizenship	Access to opportunities to participate in local voluntary groups and activities

The above outcome domains were operationalised in the current DH project on Outcomes for Disabled Service Users in one social service department in England. The domains were found to cover all areas of life for disabled service users (aged 18-65) and to adequately reflect all the needs presented to the social services teams involved in the project during 2004.

Identifying the priorities attached to the different outcome domains

One way of assessing the relative priorities that should be attached to the different outcome domains is to examine the requests for assistance that were made by working age disabled people to one social services department participating in the SPRU Outcomes for Disabled Service Users study. Data on requests for social services support were extracted from the community care assessment documents used by the whole range of professionals involved with this user group (care managers, occupational therapists, community care workers, social workers, visual impairment workers). These requests were made during two time periods (January to June/July to December 2004). During the first ('before') time period (January to June), the needs that were recorded were those expressed by service users during their community care assessment. During the second ('after') time period (July to

December) the recorded needs reflect the introduction of an outcomes-focused approach to assessment (Table 2).

Table 2: Percentge of service user needs/outcome statements categorised for the ‘before’ and ‘after’ periods

Category	*Statements of need/outcome (%)*	
	‘Before’ (n=557)	*‘After’ (n=465)*
Personal care and comfort	15.1	18.7
Access in/around the home	14.0	20.0
Equipment/aids	7.4	3.2
Transport	3.6	0.4
Financial	4.7	5.2
Transfers	8.6	10.3
Physical health/well-being	5.6	2.1
Domestic/activities daily living	9.3	5.4
Mobility	2.1	0.6
Communication	9.2	5.4
Visual	4.3	
Cognitive	0.7	
Safety and security	0.7	1.9
Housing/accommodation	2.3	1.7
Carer issues*	2.7	0.4
Employment/education/training	0.9	4.1
Social/leisure/recreation	2.3	6.4
Information/advice	0.9	0.9
Care package/hours	1.6	1.3
Parenting and relationships	0.9	1.3
Emotional well-being	0.3	1.5
Independence	0.9	7.1
Referral other professionals	0.7	
Legal	0.2	
Access community	0.9	1.7
Citizenship		0.2

Table 2 clearly shows that ‘personal care and comfort’ made up a significant proportion of the requests in both periods. However, it is also striking that this comprises only 15.1per cent and 18.7 per cent of all the recorded requests, reflecting the wide range of other requests for assistance that were received. ‘Access in and around the home’ totalled 14 per cent and 20 per cent of requests, demonstrating that this is also a core element of involvement. The other domains that comprised more than five per cent of requests were ’domestic/activities of daily living (9.3 per cent and 5.4 per cent); ‘communication’ (9.2 per cent and 5.4 per cent); ‘transfers’ (8.6 per cent and 10.3 per cent); ‘equipment/aids’ (7.4 per cent and 3.2 per cent); and ‘physical health/well-being (5.6 per cent and 2.1 per cent). Between the two time periods, during which an outcomes-focused approach was introduced, there was an increase in requests for assistance with ‘social leisure/recreation’ activities (from 2.3 per cent to 6.4 per cent); and requests relating to ‘independence’ (from 0.9 per cent to 7.1 per cent). The latter two increases are an expected part of introduction of the outcomes focus, demonstrating that when disabled people are given the opportunity, these are key areas for requested input from social services.

Table 3 shows the interventions that the social services department undertook in response to the needs/outcome requests, during the same time periods. Activities relating to the supply of ‘equipment/aids’ accounted for 41.3 per cent and 36.9 per cent respectively of all activities - the largest area of intervention by far. ‘Financial referral/application’ (which refers to benefits advice and welfare rights work) accounted for 8.5 per cent and 7.4 per cent of activities/interventions and ‘general support’ (support and monitoring) totalled 7.8 per cent and 6.1 per cent of activities. The rest of Table 3 shows a huge diversity in activity – in the ‘before’ time period alone the total for all other activities is 42.3 per cent. This demonstrates support for the ‘brokerage’ criteria discussed at the meeting as it represents the work social services undertakes in redirecting service users to other services and professionals.

Table 3: Social services interventions during the ‘before’ and ‘after’ periods

Category	*Social services interventions (%) categorised*	
	‘Before’ (n=624)	*‘After’ (n=765)*
Equipment/aids	41.3	36.9
Housing/accommodation	4.6	14.8
Financial referral/application	8.5	7.4
Referral/liaise council	0.5	1.0
Respite	1.4	0.3
Care package/hours	4.5	5.1
Moving/handling plan	0.5	0.3
Risk/handling assessment		1.2
Information/advice	5.1	3.8
Review	3.4	1.0
Monitor	2.4	0.8
Referral allied professional	1.8	4.8
Referral nursing/domiciliary service	1.3	1.6
Referral architect	2.4	0.6
Referral medical professional	0.6	0.9
Referral SI professional services	0.6	0.4
Referral visual impairments services	3.0	0.4
Referral domestic/activities daily living	1.0	0.9
Referral welfare rights	0.2	0.3
Referral day/resource centre	0.2	2.1
Referral mobility training/services		0.8
Referral one-one support services		1.4
Referral personal development course		0.6

Continued/…

Table 3 (continued)

Transport	3.8	0.9
Legal	0.5	
General support	7.8	6.1
Employment/education/training		2.0
Social/leisure/recreation	0.5	2.7
Emotional/support/counselling	0.8	0.1
Family/carer	0.5	0.1
Not eligible	2.7	0.5

Issues relating to social services activities and outcomes that are important to younger disabled people

In general, younger disabled people are assumed by service providers to have higher aspirations than older people, reflecting their different positions in the life course. Social services therefore aim to provide more than the satisfaction of basic life functions (nutrition, ablution etc.) Therefore (as Table 3 shows), activities such as facilitating access to employment, training for work or new skills, leisure and sports and support with parenting are all key areas that should be included as PSS outcome domains.

In addition, the philosophy underpinning service assessment and provision also tends to be different. Work with younger disabled people that is undertaken in a purely functional manner, reflecting a narrow concern with activities of daily living, is likely to meet with severe criticism. Issues of language and terminology are crucial in conveying, and reflecting, these differences in perspective. In general, any service that is described as aiming to improve access (to anything) would be better received by younger disabled people than a description that is purely functional. Particularly disliked is terminology that implies the disabled person is incapable and dysfunctional (such as ‘toileting’, feeding), or that is underpinned by a deficit approach. Terms such as ‘dependency’ are similarly unacceptable. The term ‘mental stimulation’ in Netten’s paper (p6) is likely to be viewed in a similar fashion. It will be important that the documentation for any work on the productivity of social services with younger (and older) disabled people appropriately reflects their aspirations.

Conclusions

In summary, five outcome domains were identified that were common to both the outcomes identified from research with younger disabled people and those proposed for older people. However, domains that are important for younger disabled people that are not reflected in the OPUS-derived older peoples’ outcome domains include:

- access to all areas of the home;
- access to the locality and wider environment;
- support for communication;

- financial security;
- emotional well being;
- access to paid employment as desired and to training and further/higher education to facilitate employment and the wider acquisition of new skills;
- access to mainstream leisure activities;
- access to support for personal relationships, including parenting relationships;
- access to advocacy/peer support and citizenship.

Ideally, all these outcome domains should be included, although some could be amalgamated for the purposes of the exercise (e.g. ‘access to employment, training, education’). The data gathered as part of the SPRU Outcomes project (Table 2) shows the breadth of requests that younger disabled people make to social services. There is a clear prioritisation of assistance with personal care and comfort, access in and around the home, domestic/activities of daily living, communication, transfers, equipment/aids, physical health/well-being, social leisure/recreation and independence. These are clearly the priority areas for service users. Reflection upon Table 3, which shows the areas of intervention that social services took action on in the same time period, shows that ‘equipment/aids’ is an area of overlap. One supplementary domain reflecting social services intervention was ‘general support’, with a final domain ‘financial referral/ application’ that can be incorporated into ‘brokerage’. The rest of the intervention profile shows a huge diversity in activity - in the ‘before’ time period alone the total for all other activities is 42.3 per cent. This demonstrates support for the inclusion of a ‘brokerage’ criterion, as it represents the work social services undertake in redirecting service users to other services and professionals.

Should the domains included in the outcomes framework developed for the SPRU project (Appendix 1) be considered too broad to be practicable, then the most important extra domains for younger disabled people are:

- equipment/aids;
- domestic/activities of daily living;
- communication;
- transfers;
- physical health/well being;
- social leisure/recreation;
- independence;
- general support/monitoring;
- brokerage.

Finally, terminology should ideally reflect younger disabled people’s aspirations. Alternatives to the terms ‘dependency’ and ‘mental stimulation’ should be sought. ‘Reliance’ might be more acceptable than ‘dependency’ as it does not contain connotation of ‘burden’. ‘Mental stimulation’ is harder to find a less stigmatising alternative for other than ‘personal interests/hobbies’.

References

Bamford,C., Vernon, A., Nicholas, E. and Qureshi, H. (1999) *Outcomes of Social Care for Disabled People and Their Carers*, Outcomes in Community Care Practice, Number 6, Social Policy Research Unit, University of York.

Harris, *et al*. (forthcoming 2005) *Outcomes for Disabled Service Users*, final report, Social Policy Research Unit, University of York.

Appendix 1

DERBYSHIRE
County Council
We're proud of Derbyshire.

DISABILITY SERVICE
COMMUNITY CARE ASSESSMENT

Completed by	Date assessment commenced
	Date form completed
Service user's name	Date of referral
Address	Source of referral
Telephone number	Date of birth
Social Services ID number	Ethnicity / culture
Religion	
Important relationships	
Address	Does not meet FACS eligibility criteria ☐
Telephone number	
Note of communication / access requirements	

Summary of presenting situation as seen by service user (including current service provision where applicable)
Lives alone

OUTCOMES ASSESSMENT

AUTONOMY OUTCOMES:	**DESCRIPTION**
Access to all areas of home	
Access to locality + wider environment	
Communicative access	
Financial security	
PERSONAL COMFORT OUTCOMES	**DESCRIPTION**
Personal hygiene	
Safety	
Security	
Desired level of cleanliness of home	
Emotional well being	
Physical health	
ECONOMIC PARTICIPATION OUTCOMES	**DESCRIPTION**
Access to paid employment as desired	
Access to training	
Access to further/higher education to secure employment	
Access to appropriate training for new skills (e.g. lip reading)	

SOCIAL PARTICIPATION OUTCOMES	**DESCRIPTION**
Access to mainstream leisure activities	
Access to support in parenting role	
Access to support for personal relationships	
Access to advocacy/peer-support	
Citizenship	

Summary of service user’s desired outcomes (goals)	Smaller outcomes (sub-goals) to be met	Who will assist the service user to achieve each of these outcomes?	Degree of urgency* (rate 1,2or 3)

1= High Priority   2=Medium Priority   3=Low Priority

Summary of service user’s desired outcomes (goals)	Smaller outcomes (sub-goals) to be met	Who will assist the service user to achieve each of these outcomes?	Degree of urgency* (rate 1,2or 3)

Does the service user agree to assist in achieving these outcomes?

Does the carer agree to assist in achieving these outcomes?

Does the worker agree that these outcomes should be planned for?

PLEASE ATTACH RELEVANT RISK ASSESSMENTS

Who participated in this assessment? **Name** **Address**	**Name** **Address**

Is the carer eligible for separate assessment?
Note arrangements to be made if so:

Summary of assessor
Specialist Assessments Required
Signature of assessor

S|P|R|U

Paper 3

MEASURING PERSONAL SOCIAL SERVICES OUTCOMES: SERVICES FOR CARERS

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 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.

---

[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.

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.

S|P|R|U

Paper 4

MEASURING AND UNDERSTANDING SOCIAL SERVICES OUTPUTS IN RELATION TO CARERS

Michael Hirst

DHP 2076 – May 2005

THE UNIVERSITY of York

List of tables

Acknowledgements

Hilary Arksey, Caroline Glendinning and Nalyni Shanmugathasan provided valuable comments and suggestions on an earlier draft. However, the views expressed are the sole responsibility of the author and are not necessarily shared by any individual, government department or agency.

Introduction

This report contributes to work led by the Personal Social Services Research Unit (PSSRU), at the University of Kent, on measuring and understanding social services activities and outputs. In the first instance, PSSRU researchers are concentrating on the outputs of personal social services (PSS) in relation to supporting older people in the community but the methodology will be extended to other client groups and carers. The work reported here focuses on PSS support for carers of disabled and older people.

Measuring PSS activities and outputs in relation to carers is complicated for reasons connected with their motivations to take on a caring role, what carers want from social services, what counts as a service to carers, how services are delivered, and how service providers recognise the role and contribution of carers. Although each caring relationship is unique in its particular aspects, most carers are motivated by an emotional commitment to, or sense of responsibility for, a close family member, partner or friend who needs help because of illness, frailty or impairment (Nolan *et al.*, 1996; Twigg and Atkin, 1994). Caregiving as emotional labour underpinned by love, compassion, gratitude, reciprocity, and fulfilment of family obligations can be a rich source of carer commitment and satisfaction. Indeed, most carers continue to care despite the physical, psychological, financial and employment costs, and loss of family, social and leisure time. Despite growing recognition of the importance of carers in legislation and guidance, and improvements in local services, most caregiving is provided in the absence of support from social services providers and practitioners (Grundy *et al*., 1999; Maher and Green, 2002). Consequently, understanding how PSS support carers in their caring roles – identifying what aspects are beneficial and measuring their contribution – is problematic. While carers often value service support, and they may want more to be available, evidence of how services enable carers to continue caring for as long as they wish or enhance the care they provide, and the period over which such effects may last, is often uncertain or ambivalent.

Moreover, service responses vary considerably depending on whether the carer is regarded as a person with needs and aspirations in their own right, and the extent to which the carer’s contribution is considered essential to the success and effectiveness of service delivery to the person cared for. Carers occupy an ambiguous position within the service system and in relation to social care practitioners. Twigg and Atkin (1994) demonstrate how the assumptions and expectations held by service providers influence both the quantity and quality of the support that carers receive. To illustrate the variety of service responses, Twigg and Atkin (1994) proposed four models for understanding how service providers relate to carers and the implications for carer support:

1. Carers as resources
   In this model, service providers and practitioners focus primarily on the cared for person as the client for service support. The carer is part of the taken for granted reality and there is little concern for the carer's needs: for example, potential conflicts between the carer and the person cared for, and the choices available to carers are ignored.

2. Carers as co-workers
   While the person cared for remains the primary focus in this model, caregiving is seen as a joint exercise. However, the carer's interests and well-being are mainly acknowledged as relevant to maintaining the quality and continuity of caregiving. Consequently, supporting the carer's role is essentially instrumental in meeting the needs of the person cared for.

3. Carers as clients
   In this model, carers are seen as people in need of support in their own right, with problems that need to be addressed explicitly. Consequently, services aimed at relieving burden or stress, enhancing the carer's morale and well-being, or enabling the carer to combine caregiving with paid work, will be considered.

4. Superseded carer
   The service providers' principal aim here is to transcend or supersede the carer's role and contribution. A key outcome is maximising the cared for person's independence, especially where the caring relationship is seen as limiting or preventing their freedom to lead an ordinary life (e.g. carers of learning disabled people or parents of young disabled people). Enabling carers to reduce or give up caregiving altogether would also be considered where that was seen as the only route to promoting their well-being.

Nolan *et al.* (1996) proposed a fifth model which sees the 'carer as expert', arguing that service providers should build explicit partnerships with carers that seek to recognise, sustain and promote the carer's expertise throughout the caring trajectory. This latter model goes beyond the notion of 'carer as co-worker' which seeks primarily to maintain the caring role, challenges the assumptions underlying the 'carer as resource', and offers a more positive basis for service support than 'carer as client' (Nicholas, 2001).

These models help to explain how carers might experience PSS provision, which can range from the facilitative to the obstructive with the former engaging carers as partners in care aiming to achieve the best possible outcome for both the carer and the person cared for, and the latter failing to appreciate the carer's needs, preferences and aspirations, and potentially adding to the carer's stress or guilt in accepting help (Nolan *et al*., 1996, pp. 47-51). However, elements of all five models may be present to varying degrees and carers' experiences may be mediated by age, sex, marital status, culturally held beliefs and practices, and employment status – greatly complicating attempts to evaluate service provision and measure carers' views of the help they receive.

A further source of complexity and variability in measuring PSS activities and outputs in relation to carers arises because there is no simple way to identify what counts as a service for carers. Twigg and Atkin (1994, p. 11f) have drawn particular attention to the support that carers often receive as a by-product of the services delivered to the cared-for person. Indeed, what carers want most from PSS is good quality services for the person cared for, to enhance or maintain their quality of life (Department of Health, 2000; Parker and Clarke, 2002). Good quality community care services for the person cared for would benefit most carers and are likely to be most effective in sustaining caregiving alongside carers' other roles and responsibilities (Pickard, 2004). Involving carers in the assessment of, and delivery of services to, the person cared for, would be an important element of improved support to carers and a key consideration in measuring the productivity of PSS outputs.

Additionally, Nicholas (2001) has drawn attention to the importance for carers of service process outcomes. These refer to the impacts of the way help is provided, including how services are organized and delivered to the person cared for, how care plans are made, and the quality of carers' interaction with practitioners and service providers. Service process outcomes also underpin the quality of carer (and client) assessment and review of needs and circumstances. Since many carers may only get an assessment, how assessments are conducted is important and may influence the perceived relevance and quality of PSS provision.

Nicholas (2001) found that carers want to be valued and respected as an individual; to have their needs and expertise recognised; to have a say in how a service is provided; to achieve a good fit between service provision and their existing routines and patterns of care; and to have a good relationship with practitioners and service providers who were accessible and responsive to changing needs (cf. Unell, 1999). 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'. Service processes can enhance or inhibit the achievement of positive outcomes for the carer's health, well-being and quality of life (Nicholas, 2001). Thus, service processes are relevant to understanding PSS activities and outputs and measuring their productivity in relation to carers.

Conclusion

This report is a contribution to work in progress being undertaken by PSSRU, and identifies several practical and conceptual challenges that need to be addressed to advance understanding of PSS activities and outputs in relation to carers. A great deal is known about the nature and pattern of caregiving, about who is caring for whom (e.g. Maher and Green, 2002). There is also a wealth of studies on the outcomes for carers and their experiences of caring (e.g. Nicholas, 2001). Evidence is also beginning to accumulate on what carers want from services and what works for carers (e.g. Unell, 1999; Pickard, 2004).

However, very little is known about the services and support packages that carers actually receive, how far services enable carers to continue in their caring roles, and how satisfied they are with the provision available. This is not surprising. The Carers and Disabled Children Act 2000 increased significantly the nature and range of services that could be provided to support carers but, as far as is known, research to monitor and evaluate its implementation from the carer's perspective has not been conducted or published. The Carers (Equal Opportunities) Act 2004 extended further the scope for social services authorities to work in partnership with health, education, employment and other local services when developing support for carers, but it is too early to assess its impact. So much more needs to be known about PSS activities and outputs in relation to supporting carers. Current difficulties identifying services for carers, and measuring what services achieve for carers, impose serious limitations on and risks of misrepresenting the role, contribution and effectiveness of PSS to carer support.

Outline of the report

This report concentrates on three aspects that are crucial to measuring and understanding PSS activities, outputs and outcomes in relation to carers:

1. Estimating the quantity of PSS outputs delivered to carers; that is, the number of carers receiving PSS and how much support they get.
2. Assessing the extent to which carers rely on PSS to look after the person cared for and sustain their caring roles; that is, carer's capacity to benefit from PSS.
3. Evaluating carers' views about the quality of, or satisfaction with, PSS provision.

These three components form the core element of the welfare index being developed by PSSRU researchers to measure the outputs of PSS expenditure. Each is discussed in turn in the following chapters.

Measuring the quantity of personal social services outputs for carers

Introduction

The methodology being developed for measuring the productivity of personal social services (PSS) in relation to carers of adults requires an estimate of the quantity of service supplied to carers during a specified period. It is clear that reliable estimates of PSS support received by carers will have to be gathered centrally from information initially collected by local councils with social services responsibilities. The most useful information on PSS activities and outputs is currently collected in the annual summary of the number and types of Referrals, Assessments and Packages of Care in Adult Personal Social Services, or RAP for short. Carers' assessments and services to carers are covered explicitly in the RAP data collection process.

The chapter has three aims: to review the current RAP return on carers, consider whether the RAP process provides a reliable basis for estimating the quantity of PSS consumed by them, and make recommendations. The discussion concentrates on identifying the information needs and priorities for measuring PSS activities and outputs in relation to carers. The purpose, therefore, is not to evaluate whether the RAP data collection process achieves the specific purposes around performance assessment for which it was designed.

The next section describes the nature and scope of the data on carers collected in the RAP return. Later sections describe the measures of service quantity that can be derived from the current RAP return and their limitations. Recommendations for enhancing the usefulness of the RAP process for measuring PSS outputs in relation to carers are then discussed. It is recognised that revising the RAP data collection raises important ethical, financial, technical and practical issues. These issues are likely to be more challenging than reaching a consensus on information needs; however, they are beyond the scope of this article.

The current RAP return

For the year ending in March 2006, data on carers of adults will be summarised in four RAP returns. Each is described in turn below.

Two forms in the carers RAP return, reproduced here as Tables 2.1 and 2.2, record the number of carers' assessments or reviews carried out during the accounting period. The first form breaks this information down by the age group of the carer (Table 2.1).

Table 2.1 Number of carers assessed or reviewed by age group of carer

Age of carer	*Number of carers assessed or reviewed separately*	*Number of carers assessed or reviewed jointly with the client*	*Number of carers declining an assessment*
Under 18			
18 to 64			
65 to 74			
75 and over			
All ages			

The assessments recorded in this table cover assessments of carers' needs carried out under the Carers and Disabled Children (CDC) Act 2000 (Department of Health, 2001a, b, c). An assessment is defined as the first assessment for a new carer; all subsequent assessments or reassessments are defined as a review. The term client refers to the person cared for.

The table counts carers of adults (people aged 18 and over) but not carers or parent carers of children and young people aged 17 and under. Although the CDC Act 2000 covers carers aged 16 and over only, younger carers of adults are included in the RAP return. It can be seen that the table distinguishes between carers assessed or reviewed separately from the client and carers assessed or reviewed in conjunction with the assessment of the cared for person's needs for community care services. The table also counts the number of carers declining an assessment.

If a carer has been assessed or reviewed more than once during the accounting period, only their latest assessment or review is recorded. There are no restrictions on who carries out the carer's assessment, or part of it. Councils may fulfil their statutory duty of assessment themselves or as part of a joint health and social care team. Councils can also contract out the assessment process to other organisations but these assessments are included in the RAP return only where councils have funded the process and satisfied themselves that each individual assessment is fair, valid and comprehensive according to current guidance.

The second RAP form presents the information on carers' assessments according to the client group of the person cared for. Five client groups, broken down into two age bands (18 to 64, and over 65), are distinguished as shown in Table 2.2. Otherwise, the column headings of Tables 2.1 and 2.2 are identical.

Table 2.2 Number of carers assessed or reviewed by client group of the person cared for

Client group of person cared for by carer	*Number of carers assessed or reviewed separately*	*Number of carers assessed or reviewed jointly with the client*	*Number of carers declining an assessment*
Client aged 18 to 64			
Physical disability, frailty and sensory impairment			
Mental health			
Learning disability			
Substance misuse			
Other vulnerable people			
Total			
Client aged 65 and over			
Physical disability, frailty and sensory impairment			
Mental health			
Learning disability			
Substance misuse			
Other vulnerable people			
Total			

The two remaining carer RAP forms record the services put in place following an assessment or review during the accounting period. These may be provided directly by social services or by another organisation on behalf of social services. If the carer is assessed or reviewed more than once during the period, only the outcome of their most recent assessment is recorded. However, services that are continuing from a previous assessment, as well as any new services agreed following a review, should be recorded. Where the assessment or review takes place near the end of the accounting period and the services have not yet been put in place, the services agreed following assessment or review are recorded.

The RAP return records the types of service provided according to the age group of the carer (Table 2.3) and the client group of the cared for person respectively (Table 2.4).

Table 2.3 Number of carers receiving different types of services provided as an outcome of an assessment or review by age group of carer

Age of carer	*Services including breaks for the carer and/or other carers' specific services*	*Information and advice only*
Under 18		
18 to 64		
65 to 74		
75 and over		
All ages		

From the column headings of Tables 2.3 and 2.4, it can be seen that three broad types of services for carers are distinguished in the RAP return:

1. Breaks for carers
   A breaks service is defined as one that actually gives the carer a break from direct responsibility of supervising or caring for a person by providing a service for that person. A service is counted as a breaks service where it has been provided after the carer has been assessed as needing a break, that is where the service will benefit primarily the carer.

2. Other specific carers' services
   Specific services for carers are not defined as such and may take any form provided that, following an assessment of need, the service will support the carer in their caring role and help them maintain they own health and well-being. This category would include direct payments, which can be given in lieu of carers' services under the CDC Act 2000.

3. Information and advice only
   The provision of information and advice, including welfare benefits information and advice, is recorded in the carers' RAP return where the service is a one-off activity. Information and advice that involves an ongoing financial or resources commitment is counted as a specific carers' service.

Table 2.4 Number of carers receiving different types of services provided as an outcome of an assessment or review by client group of the person cared for

Client group of person cared for by carer	*Services including breaks for the carer and/or other carers' specific services*	*Information and advice only*
Client aged 18 to 64		
Physical disability, frailty and sensory impairment		
Mental health		
Learning disability		
Substance misuse		
Other vulnerable people		
Total		
Client aged 65 and over		
Physical disability, frailty and sensory impairment		
Mental health		
Learning disability		
Substance misuse		
Other vulnerable people		
Total		

Each carer receiving a service appears only once in each return shown in Tables 2.3 and 2.4. Where carers receive all three types of services, they are recorded in the second column because their service package includes at least one breaks service and one specific carers' service. Carers receiving breaks services only, specific carers' services only, or both, are also recorded in the second column. Carers receiving only information and advice, and neither a breaks service nor a specific carers' service, are recorded in the third column.

Summary measures from the RAP return

The following measures of PSS activity and output in relation to carers can be derived from the current RAP return:

1. Total number of carers offered an assessment or review during the accounting period.
2. Total number of carers receiving an assessment or review during the accounting period.
3. Total number of carers receiving an assessment or review jointly with the cared for person during the accounting period.

4. Total number of carers receiving an assessment or review separately from the cared for person during the accounting period.
5. Total number of carers declining an assessment or review during the accounting period.
6. Total number of carers receiving breaks services, or other specific carers' services, or both, following an assessment or review conducted during the accounting period.
7. Total number of carers receiving advice or information (but not breaks services or other specific carers' services) following an assessment or review conducted during the accounting period.
8. Total number of carers receiving services or direct payments following an assessment or review conducted during the accounting period.

Each of these totals can be broken down by the carers' age group; they can also be broken down by the client group of the cared for person, the age group of the cared for person, or by both the client group and the age group of the cared for person.

Evaluating RAP data on carers

The RAP return on carers is intended primarily to provide the information required for calculating the carers' performance indicator as well as monitoring the development of carer support at the local level to inform policy and the Spending Review. The return was not intended to measure service activities and outputs and, as will be explained, does not currently provide a robust, reliable or valid measure of PSS consumed by carers. In brief, the RAP return both underestimates and misrepresents PSS activities and outputs as they relate to carers; this happens for several reasons:

- The total number of carers supported during each accounting period is not known. This arises mainly because the RAP return counts only those carers who had an assessment or review during the period. Carers who receive a service following an assessment or review conducted during a previous accounting period would not be included in the current RAP returns. These carers are likely to form a majority of those who are supported at any one time.

- The total number of assessments and reviews conducted during the accounting period is not known because, where a carer is assessed or reviewed more than once during the period, only the most recent assessment or review is recorded. However, the extent of the shortfall may be quite small on average.

- The number and quantity of services to carers are not precisely known. This arises primarily because the support currently received by carers who were assessed or reviewed in a prior accounting period is not recorded and, as already indicated, they are likely to form a majority of the carers receiving PSS. Additionally, only the outcomes of the most recent assessments or reviews are recorded; services received earlier in the current period but discontinued after the latest review are not included. The method of accounting also understates the total volume of provision because carers who receive service support as an outcome of a recent assessment or review appear just once in each RAP table (including those who care for more than one person). Thus, the RAP return does not have separate entries for the number of carers receiving breaks services, specific carers' services, or both, and the provision of information and advice is recorded only if neither a breaks service nor any specific carers' service is provided. Consequently, it is not possible to estimate how many carers actually receive each type of service or service package.

- Moreover, a full enumeration of service provision to carers would require a detailed break down of the three broad types distinguished in the RAP return. Breaks services, for example, 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. Each type of provision has quite different implications for PSS activities and outputs. Specific services for carers, which can include direct payments, are also extremely diverse, as is the provision of information and advice, again with varying demands on the use of PSS resources. As well as distinguishing more precisely each type of service, a full account of PSS devoted to carers would require estimates of the quantity of services delivered; for example, the amount of time during the accounting period that carers were given a break from their caring responsibilities.

- The number of carers supported as a by-product of community care services to the cared for person is not recorded in the RAP return unless the service is intended primarily to benefit the carer. For example, day care often gives carers a break from their caring responsibilities but would not be recorded as a breaks service where the intention is to support the person cared for. Similarly, home care, meals or transport provided to the cared for person often benefit carers indirectly but this would rarely be captured in the carers' RAP return. When completing the RAP return, councils are required to decide whether a service is for the client or for the care. Where the service is for both, councils are expected to decide whether the client or the carer benefits most from the service. Needless, to say such judgements are not easy and introduce an artificial distinction to the assignment of service outputs and outcomes.

- Carers' services funded by councils but provided by other organisations are recorded in the RAP return only where they have been agreed following an assessment of carers' needs under the CDC Act 2000. Other services to carers provided by organisations receiving PSS funding would not be counted. Carers' centres run by the Princess Royal Trust for Carers with council grant funding represent the kind of provision that would not be fully captured by RAP returns. Carers may access such centres for advice and information, training in care tasks, counselling or emotional support for example, without referral or assessment by social services. However, a proxy measure for carers' services not included in the RAP return is available in councils' PSS expenditure returns to the Department of Health. These returns include the amount of revenue provided as grants to organisations to provide services that are not specified in carers' assessments.

- Some carers get direct payments in lieu of services to meet their support needs following an assessment and, as noted above, they are captured in the RAP return as receiving a specific carers' service. However, the services they purchase on their own behalf are not recorded. A proxy measure is available from councils' PSS expenditure returns, which record the number of carers receiving direct payments on 31 March of each accounting period. It should also be possible to estimate the average direct payment per carer.

- Doubts have also been expressed about the quality of RAP data. The Audit Commission, for example, has questioned the coverage of councils' routinely collected data on carers' assessments and the recording practices they employ. The Commission raised the issue after finding inconsistencies between the official returns and their own reviews of recently opened case files and local surveys of carers drawn from councils' databases (Audit Commission, 2004, pp. 43-50). Other variations in the quality of the RAP data collection process might also arise because some councils conduct a full count of their case files while others base their return on a sample. If a sample was used, councils are asked to describe the process in the RAP return but it is not known how the different methods used affect the quality and completeness of the RAP data.

Because of these limitations in the design and content of the RAP return, the number of carers supported by PSS expenditure during an accounting period is not known, nor is it possible to estimate the total volume of PSS activity devoted to the assessment and support of carers. Service outputs covering the amount and type of support received by carers are not recorded, and service packages or the way services are combined for particular groups of carers are not distinguished.

Difficulties using the RAP returns to quantify PSS activities and outputs are likely to increase when investigating changes over time in service provision. For example, the lack of an observed change in the number of carers receiving breaks services or other specific carers' services, recorded in the second columns of Tables 2.3 and 2.4 above, could mask significant shifts in the numbers receiving either or both types of support. Similarly, an increase or decrease in the number of carers receiving breaks services or other specific carers' services could have quite different implications for PSS expenditure, activity and output depending on precisely what types of provision for carers were expanding or declining, and by how much. In short, changes over time in carers' services are difficult to monitor and interpret, and their implications for PSS productivity impossible to evaluate reliably. Discontinuities in RAP returns also occur because of changes in their scope and content, new guidance on how the returns are to be completed, and improvements in the data held at the local level.

By comparison, the RAP data on assessments and reviews is probably more robust for time series analysis. Although these data underestimate slightly the total number of assessments and reviews conducted during each accounting period, it seems reasonable to assume that the level of undercounting remains constant over time, so observed trends would be more reliable.

Revising RAP returns to measure PSS outputs and productivity

The current return could be improved by expanding the scope of the data collection and by changing the way in which services to carers are recorded. The scope of the RAP return could be expanded from carers that are assessed or reviewed during the accounting period, to include all carers that received a service during the accounting period or during a specified week. This would provide a more complete picture of service provision for carers. A major barrier to achieving this would be the additional burden placed on councils and their ability to deliver the enhanced dataset.

As far as is known, there are no plans in the pipeline to change any details of the carers' RAP return for 2005/2006 or beyond. A proposal to collect information on the ethnicity of carers was considered but not agreed, and is not expected to be raised again in the immediate future. More importantly for present purposes, consideration has been given to recording the number of carers receiving specific carers' services other than breaks services, but this option has not been taken forward. Whatever their individual merits, all such proposals have to be judged against increasing the complexity of the RAP return, the administrative burden on social services departments, and their impact on data quality.

A major obstacle to revising and extending the current RAP return stems from the current approach which collects data from local authorities in aggregate form; that is, on sub-groups of carers defined by age, client group of the person cared for, assessment context, and so on. This makes it difficult to introduce new variables without creating increasingly complex returns. Thus, the requirement for information about carers' assessments and services by the client group of the cared for person, was more easily accommodated by introducing additional forms (Table 2.2 and 2.4 above) than by redesigning the existing ones (shown in Tables 2.1 and 2.3). Additional information, on carers' ethnicity for example, would probably require extra forms to avoid making the current ones too complicated to complete and use. Information summarised in aggregate form also limits further analysis because cross-classification of data summarised in different tables, for example the age of the carer by the age of the person cared for, is not possible.

To overcome these limitations, a more radical approach to collecting data on carers has been proposed by those responsible for overseeing the RAP process but was rejected by local authorities as too burdensome. The suggestion was to collect a single line of data for each carer assessed or reviewed during the accounting period. To collect the current RAP data in this form, the new return might look like Table 2.5. The totals and sub-totals of carers that are currently entered in the RAP return would then be obtained by computing summary statistics from the individual data held in a spreadsheet.

However, the format illustrated in Table 2.5 would fail to capitalise on the possibilities for constructing a comprehensive and flexible database. For example, carers' and clients' ages (rather than age group) could be recorded in columns 1 and 7 respectively, or better still dates of birth which would allow their ages to be updated. Column 4 could be sub-divided into two columns: one for breaks services and one for other specific carers' services. Within each of these columns, classifications could be devised to represent the different types of service that individual carers received (for example, whether the breaks service covered day care or overnight care, and whether it was provided in the cared for person's home, in a host family's home, or in a communal or institutional setting). An additional column might record the number of days or weeks during the year that carers received as a break from their caring responsibilities. Similarly, advice and information could be classified according to its scope, content and format, and whether it was provided as a one-off activity or an ongoing service. A separate column could record the amount received in direct payments.

Alternatively, a separate column for each type and sub-type of service could be created so that cell entries would simply record whether or not it was received and, where appropriate, how much. This design would offer greater flexibility for future expansion of the dataset, and might link more easily to improved local management information systems for handling individual case files. Extra columns could incorporate further details, on carers' ethnicity for instance, or the services received by the person cared for. If additional columns also contained the dates of carers' first assessments and their latest reviews, details of all carers receiving PSS during the accounting period could be extracted. Assessed needs and outcomes information could also be incorporated.

In this way, a comprehensive picture of PSS activities and outputs as they affect individual carers could be built up. As well as counting the number of carers supported and describing their care packages, detailed statistics could be readily produced, including annual summaries and time series. Such information would become a rich source of data and analysis for policy makers and service planners, as well as having other applications beyond the current concern with measuring PSS support for carers. In particular, they would provide a sound basis for drawing samples of carers for conducting local satisfaction surveys, monitoring non-response rates and who is reached. The possibilities for developing a comprehensive data collection system along these lines has been considered by those responsible for the RAP process but has been rejected for the time being.

Table 2.5 Hypothetical information on individual carers

1	*2*	*3*	*4*	*5*	*6*	*7*
Carer ID	Carer's age group	Assessment or review	Breaks service or other specific carers' service	Information and advice only	Client group of person cared for	Age group of person cared for
001	2	1	1	2	2	2
002	3	2	2	1	1	2
003	2	3	2	2	5	1
etc.						
Codes:	1= Under 18 2= 18 to 64 3= 65 to 74 4= 75 and over	1= jointly 2= separately 3= declined	1= yes 2= no	1= yes 2= no	1= Physical disability, frailty and sensory impairment 2= Mental health 3= Learning disability 4= Substance misuse 5= Other vulnerable people	1= aged 18 to 64 2= aged 65 and over

Conclusions

The RAP returns provide valuable information about carers' assessments and services. However, these data seriously underestimate the extent to which PSS currently support carers. They are also inadequate in terms of coverage and detail for measuring service activities and outputs in relation to carers, and for interpreting changes in service provision over time. Individualised records of the support packages that carers received would overcome these limitations and provide the basis for developing a more comprehensive and flexible dataset. To be acceptable to social services authorities, the reorganisation of the RAP data collection process along these lines would probably depend on the development of a management information system for delivering integrated information about individual service users and carers. The introduction of such a system would in turn need to be linked to wider changes in routine practice and recording by service managers and front-line practitioners.

Responsibility for the RAP collection process moved from the Department of Health to a new body called the Health and Care Information Centre in April 2005. The new Centre plans to fundamentally review the information collected on adult social care including carers. It is likely that the introduction of individualised records will be considered as part of that review. If agreement is reached on a new approach, implementation could follow within two or three years, or longer depending on local authorities' resources for developing the systems required and supporting the changes in practice that would follow.

Carers’ capacity to benefit

Introduction

A key term in the PSSRU model being developed to measure PSS outputs is ‘capacity to benefit’. This refers to the level of well-being that could be delivered by a service assuming perfect quality and taking into account the characteristics and needs of service users. In relation to carers, capacity to benefit refers to their reliance or dependence on personal social services to meet their needs as a carer, in their caring role. More precisely, capacity to benefit is the degree to which carers depend on a service to meet their needs in the areas that the service affects: it links what services do (in terms of outcomes for carers) and how much they do (in terms of carers’ reliance on services) for each service.

For example, carers may be offered a breaks service to maintain their health and well-being (the outcome domain); in this case, capacity to benefit indicates the degree to which carers rely on breaks services to maintain their health and well-being. Consider another example: the person cared for may be offered day care to enable the carer to have a life of her own; in this domain, carers’ capacity to benefit indicates how much they depend on day service provision to fulfil their other roles and responsibilities, and participate in non-caregiving activities.

For each outcome domain, PSSRU researchers are aiming to identify four levels of dependence on a service:

1. No need for assistance
2. All needs met
3. Low level (unmet) needs
4. High level (unmet) needs.

Capacity to benefit is assumed to be the difference between low or high level needs and all needs met or, where appropriate, the difference between these need levels and no need for assistance. The degree to which services meet users’ needs in each outcome domain would be ascertained from responses to a standardised survey questionnaire.

Carers might be expected to benefit from social care services in several outcome domains including: being in control of their own lives, participating in social activities and leisure pursuits, combining paid work and caregiving, as well as being supported in their caring role and responsibilities.

This chapter focuses on Role Support because, as indicated in the introductory chapter, it is difficult to define how services relate to this domain and measure the degree to which carers rely on services to support their caring role. Carers’ capacity to benefit in this domain is about enabling them to continue in a role which most will have entered from a strong emotional commitment to, or sense of responsibility for, a close family member, partner or friend who ill, frail or disabled (Nolan *et al*., 1996). In most cases, the potential or actual contribution of services is unlikely to have been a factor influencing the decision to take on a caring role, and most carers would continue providing care in the absence of any support from formal services and practitioners.

There is therefore no simple, straightforward way to assess the degree to which carers rely on personal social services to carry out their caring responsibilities. The immediate requirement is to identify an appropriate conceptual framework for developing a measurement model that reliably distinguishes carers' dependence on services. Five approaches are suggested here and each is discussed in turn.

1. Coping with the demands of caregiving

This approach rests on the notion that services to carers are intended to help carers cope with or manage the challenges of their caring role. In the research literature, the demands of caregiving are often considered within the stress-appraisal-coping paradigm, which draws attention to the interaction between the carer and the care situation, the resources available to the carer, and the strategies she adopts (Nolan *et al*., 1996). Within this framework, services would be seen as resources that enhance carers' coping strategies, including services that offer training and support in developing new strategies.

The concept of coping informs PSSRU's current proposal for assessing carers' reliance on services. The intention is that carers would be asked to select one of the following statements to distinguish the four levels of capacity to benefit:

a. You are providing someone you care for with the quality of support that you want.
b. You are not providing someone you care for with the quality or type of support that you would wish.
c. At times you find it difficult to cope with the demands of caring.
d. You frequently find it very difficult to cope with the demands of caring.

This approach will be piloted shortly and subject to cognitive testing. As they stand, the statements appear to question the carer's competency or ability to provide care. This may not be an appropriate assumption given that carers often criticise social services assessments for implying as much.

An alternative approach to rating carers' coping efforts might be to adapt the checklist developed by Nolan *et al*. (1998). Called the Carers Assessment of Managing Index (CAMI), this checklist identifies the coping strategies that carers use and their perceived effectiveness, rather than asking directly whether they feel able to cope or not. CAMI focuses on strategies aimed at managing events or problem solving, managing meanings or perceptions about the care situation, and managing stress associated with caregiving. Thirty-six strategies are described altogether and each is rated from ‘very helpful’, through ‘quite helpful’ and ‘not really helpful’, to ‘not used’.

What is proposed here is that some or all of the strategies in CAMI could be presented to a representative sample of carers who have been assessed by social services. Their responses would then be combined and scaled to represent the degree to which carers are managing effectively or have unmet needs for advice, information and support. With further testing and development, the aim would be to identify and define four levels of coping effectiveness that could be used as an alternative to those proposed by PSSRU to weight a capacity to benefit indicator.

2. Sustainability of the caring role

The second approach focuses on the sustainability of the caring role. Guidance to local authorities on the implementation of the Carers and Disabled Children Act 2000 recommends that assessment of carers’ needs should consider the risks to sustainability and the help that services can provide to support the caring role (Department of Health, 2001a, b, c). Practitioners are required to consider the following factors when assessing the sustainability of the caring role:

a. Autonomy. This dimension concerns the carer’s freedom to choose the nature of the tasks they will perform and how much time they will give to their caring role.
b. Health and Safety. Here the risks to the carer’s own health of maintaining their caring role at its current level are considered.
c. Managing daily routines. The consideration here is whether carers can look after their own domestic needs and other daily routines while sustaining their chosen caring role.
d. Involvement. This aspect considers the extent to which carers have freedom to maintain relationships, employment, interests and other commitments alongside their caring responsibilities.

(Department of Health, 2001b, p. 25)

The extent of risk is the degree to which a carer’s ability to sustain that role is compromised or threatened either in the present or in the foreseeable future by the absence of appropriate support. Risk is graded from critical, substantial, moderate to low, and the practice guidance gives detailed descriptions of the criteria for deciding levels of risk (reproduced here in Annex A).

The risk assessment model could be applicable to measuring capacity to benefit if threats to, or difficulties in, sustaining the caring role indicate the extent of carer’s unmet support needs and dependence on services. This assumption appears to underpin policy guidance in that the provision of services and support to carers is intended explicitly to help manage and reduce risks to sustainability. The risk assessment approach, therefore, could form the basis for developing and testing a survey instrument for distinguishing need levels and measuring carers' reliance on service support.

One way to carry this proposal forward would be to develop a battery of questions that capture the issues considered in a risk assessment of caring roles, more or less along the lines of those identified in the official guidance (see Annex A). Testing and development might involve several rounds of fieldwork and statistical scaling to identify key items that reliably distinguish risk levels, which could then be used in routine surveys to assess carers' dependence on service support.

3. Opportunity costs of caring

The literature on carers has long drawn attention to the opportunity costs of caring, that is the opportunities foregone in order to fulfil caring responsibilities. More recently, opportunity costs have been explicitly recognised in the Carers (Equal Opportunities) Act 2004, and in the guidance to the Carers and Disabled Children Act 2000 (Department of Health, 2001a, b, c).

Thus, PSS can be provided to reduce or avoid opportunity costs to carers, for example by enabling them to fulfil other family roles, stay in paid employment, participate in learning and training activities, or generally to have a life of their own. The notion of opportunity costs might therefore provide an appropriate conceptual framework for measuring carers' reliance or dependence on services: the greater the opportunity costs, the greater the capacity to benefit. As with the other approaches suggested here, this would require an intensive period of testing and development; in this case, the aim would be to identify key questions or statements that could reliably differentiate the degree to which carers experience opportunity costs arising from their caring responsibilities.

4. Best possible care for the person cared for

The notion of an ideal or optimum care situation for both the carer and the person cared for, informs in part the argument that a key function of PSS providers and practitioners is to work in partnership with carers and enable them to provide the highest quality of care for the cared for person (Nolan *et al*., 2003). Carers themselves often voice the opinion that they want to provide the best possible care for the person they care for, and to have their caring role recognised and valued by service providers (Nolan *et al*., 1996; Twigg and Atkin, 1994). Following this line of reasoning, survey questions could be developed around the extent to which carers feel able to provide the best possible care, or whether the quality of their caregiving is somehow compromised or less than they aspire to provide. The more carers felt unable to provide the highest quality of care, the more they might be considered reliant on service support.

A potential problem with this approach is that the wording of statements or questions to establish levels of need could be quite tricky if they were to avoid any implication that carers might be considered incapable or negligent. A further complication, at least as far as implementing the PSSRU model is concerned, is that carers' responses to such questions might be shaped by their perceptions of the quality of services for themselves and the person cared for, as well as the quality of their relationship with service providers. Since service quality and service process outcomes are already captured in the PSSRU model, such duplication would have to be avoided.

5. A fulfilling caring role

A possible variant of the previous approach, which might avoid the difficulties identified, would be to assess the extent to which carers find caregiving to be rewarding or fulfilling. Nolan *et al*. (1996, p. 106) argue that successful interventions for carers are about minimising the difficulties and stressfulness of caring while maximising the satisfaction and sense of achievement that caring can bring. Following this line of reasoning, the degree to which carers realise satisfactions and rewards from their caring role would indicate levels of need for and dependence on service support.

An approach built around the notion of a fulfilling caring role could draw on the checklist developed by Nolan *et al*. (1998) to identify the rewards and satisfactions of caring. Called the Carers Assessment of Satisfactions Index (CASI), this checklist asks carers about sources of satisfaction in their caring role and the extent to which these are perceived to represent positive outcomes for themselves and the person cared for. Each source of satisfaction is rated by carers from 'a great deal', through 'quite a lot', and 'no real satisfaction', to 'does not apply', to assess the extent to which it applies to their care situation. Combining and scaling these responses to provide an indication of capacity to benefit assumes that services for carers are intended to maintain or enhance the rewards and satisfactions of caring.

CASI contains 30 statements although not all may be appropriate for measuring capacity to benefit. A complementary checklist developed by Nolan *et al*. (1998), the Carers Assessment of Difficulties Index (CADI), may also contain statements that could be adapted for measuring capacity to benefit. Indeed, the two checklists could provide a balance of positive and negative statements for assessing carers' experiences. For instance, a combined checklist might include statements such as 'I don't have enough time for myself' (CADI) and 'Caring has allowed me to develop new skills and abilities' (CASI). Both checklists were developed from a research-based rationale which linked carers' experience of stress and coping with the perceived rewards of caring. They seem to work well as a research tool and appear to be useful in a practice context. Thus, Nicholas (2003) has piloted their use in developing an outcomes focus to carer assessment and review. Additionally, Hepworth (2003) has tested versions of CASI and CADI in Gujarati and Urdu for use with Asian carers to assist local authorities in improving assessment and support for ethnic minority carers (see also Hepworth, 2005).

Conclusion

Five approaches to assessing carers’ need levels for weighting their capacity to benefit from a service have been outlined. Each approach has its own merits and some basis in the literature. As already suggested however, each approach requires further development and testing to ascertain how well it performs in practice in providing a meaningful representation of unmet need and reliance on services that is acceptable to carers.

A possible way forward would be to evaluate the strengths and limitations of each approach in a single survey of eligible carers who have been recently assessed or reviewed by social services. It is clear for example that the approaches identified are not mutually exclusive. Thus the CADI statement, ‘I don’t have enough time for myself’, addresses directly one of the opportunity costs of caring. Similarly, opportunity costs related to paid employment are likely to figure when assessing the sustainability of caring roles. Coping and risk to sustainability are also linked in that carers who are coping well and deploying a range of coping strategies effectively are probably in a care situation that is not at risk of breaking down. Moreover, carers’ satisfactions and difficulties are likely to be associated with how well they feel they are coping with the demands of their caring role. So there is some useful work to be done investigating associations between different ways of conceptualising carers’ needs for support in their caring roles, and increase understanding of the diversity of care situations and carers’ experiences.

An alternative way forward would be to select the approach that, on the face of it, appears to offer the best model for assessing carers’ need levels and reliance on services. Consultations among colleagues in SPRU indicate that if one approach were to be selected, ‘sustainability of the caring role’ would be the preferred option. Several reasons can be advanced to support this choice. Importantly, assessing the sustainability of caring roles would relate directly to what happens during carer assessment and review if practitioners are following current guidance. Thus, exploring the sustainability of caring roles with carers probably comes closest to understanding how they feel their caring role is recognised, regarded and supported by service providers. More immediately for the purpose in hand, assessing the sustainability of caring roles would appear to be an appropriate framework within which carers can be asked directly about their support needs and the extent to which services can be realistically expected to meet them. An additional advantage of developing an approach from a model that is currently endorsed in the guidance on carer legislation is that it might draw on decision aids developed by practitioners for assessing risk to sustainability.

Measuring the quality of personal social services outputs for carers

Introduction

The methodology being developed for measuring the productivity of personal social services (PSS) in relation to carers of adults requires a quality measure or weight for each service supplied. This weight is intended to represent both the degree to which a service is meeting carers' needs and the processes of service delivery, including the way the service is delivered to carers and the way staff interact with carers. Including a quality weight enables the methodology to capture changes over time in service delivery and practice, as well as changes in carers' expectations of the services they receive.

In the absence of valid and reliable data on the quality of carers' services, further research will be required to develop and test appropriate measures and produce estimates that are representative of the carer population receiving PSS. More immediately, there is a need to identify an appropriate model for measuring carers' views on the quality of PSS, and this is the primary focus here. Fortunately, a great deal of work, overseen by the King's Fund, on developing a quality assurance scheme for carers' services has been undertaken since the National Strategy for Carers identified a need to secure service improvements in carer support (Department of Health, 1999, pp. 66-7).

The approach adopted by the King's Fund may be described as 'standard setting', that is, establishing quality standards for a satisfactory service against which carers can make judgements about their experiences of the services they actually receive. An important advantage of assessing carers' views of service quality against agreed standards is that it can provide a middle way between satisfaction ratings that may be boosted by low expectations, and satisfaction ratings that may be depressed by impractical expectations in a context of limited resources. Ideally, carers themselves and their organisations, as well as policy makers, service planners and practitioners, should agree the standards. The process might also include disabled and older people, carers' families, and members of society in general. The aim is to develop a consensual model of expectations about how services for carers should be. This was the approach taken by the King's Fund.

Quality standards for carer support services

The process of setting standards for carers' services began with a review of the literature on what carers say about services and service quality, and a survey of statutory and independent organisations, including carers' organisations, of work in progress towards developing quality standards (Unell, 1999). In her review, Unell identified five dimensions along which carers assess services. These dimensions and the quality issues associated with them are listed in Table 4.1. Unell provides further explanation from the literature about what each quality issue means in practice for carers.

Table 4.1 Quality issues for carers

Dimension	*Quality issues*
1. Being informed	Comprehensiveness
	Accessibility and responsiveness
	Timeliness
	Expertise
	Partnership
	Empowerment
2. Time off	Appropriateness
	Availability
	Choice
	High standards of personal care
	Flexibility
	Timeliness
	Partnership
3. Emotional support	Sensitivity to carers' emotional needs
	Continuity
	Accessibility
4. Training and support to care	Appropriateness to needs and circumstances
	Responsiveness in a crisis
5. Financial security	Adequacy of income
	Adequacy of information
	Awareness and responsiveness on the part of employers
	Flexibility on the part of services in relation to carers in employment

Following Unell's review, a further round of consultation with carer, voluntary sector, health and social services networks led to the publication of *Quality Standards for Local Carer Support Services*, which was endorsed by the Department of Health (2000). This report divides the standards into two parts as recommended by Unell. The first part is a statement of what is to be achieved by a service delivering a particular output for carers (for example, taking a break from their caring role). The second part identifies a set of criteria or measures describing how that is to be done, or how the service is to be delivered, to achieve the best possible outcome for carers (for example, by looking after the care recipient in a way that gives carers confidence and trust in the breaks service).

The DH report proposed five key standards as shown in Table 4.2. These more or less follow Unell's typology with two exceptions. Financial security was not included as a standard because it was felt that this issue primarily concerned adequacy of income which was beyond the scope of carer support services; however, the provision of advice and information about financial matters, including benefits, is covered under the dimension concerned with the quality of information. Secondly, a new dimension concerned with giving carers a voice was added because of its importance in related work, also conducted by the King's Fund, on developing a tool – known as the 'Carers Compass' – for use in audit and performance management for improving support to carers (Banks and Cheeseman, 1998a).

Table 4.2 Quality standards for carer support services

Dimension	*Quality issues*
1. Information	Any service providing information to carers provides information which is comprehensive, accurate and appropriate, accessible and responsive to individual needs.
2. Providing a break	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.
3. Emotional support	Any service offering emotional support to carers, either on a one-to-one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers.
4. Support to care and maintain carer's own health	Any service which supports carers to care and to maintain their own health and well being by offering training, health promotion and personal development opportunities is responsive to individual needs.
5. Having a voice	Any service which supports carers to have a voice as an individual and/or collectively is accessible to all carers and is able to act in an independent way.

The quality standards outlined in the DH report subsequently featured in the guidance for the Carers and Disabled Children Act 2000, and in the guidance on use of the Carers Grant (Department of Health, 2001b, p. 5). More recently, Blunden (2002) produced a guide and checklists based on the DH report for service planners and those who commission services, as well as for carers and their organisations, to use as a resource for checking the quality of local carer support services. Blunden also proposed a series of questions for eliciting carers' views and experience of the support they receive. These questions could form the basis of a questionnaire survey of carers to obtain their judgements or ratings of the quality of services and the processes of service delivery.

The remainder of this note summaries Blunden's guide for measuring the quality of carers' services. It then outlines a number of tasks and issues for which further research is required to address.

Evaluating the quality of carer support services

As described above, quality standards have been developed for five service outcomes that carers say are important, and for each standard there is a set of criteria describing how it is to be achieved. These standards are designed primarily for services aimed exclusively at supporting carers, but they are equally relevant to other services that must take into account the carer's role and contribution.

The standards and criteria are summarised in Table 4.3, alongside Blunden's recommendations for obtaining feedback from carers.

Table 4.3 Quality standards and checklist for carer support services

Dimension	*Standard*	*Quality criteria*	*Feedback from carers*
1. Information	Any service providing information to carers gives information that is comprehensive, accurate and appropriate, accessible and responsive to individual needs	a. Comprehensive b. Accurate and appropriate c. Accessible d. Responsive	• Has this service given you information about what support you can get? • Did you get all the information you needed? • Did you get the chance to discuss the information with someone face-to-face? • How clear was the information? (Could you understand it? Was it available in your language?) • Was the information up-to-date? • Has the service dealt with your enquiries promptly? • Has the service treated you courteously?
2. Providing a break	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	a. Works in partnership b. Flexible and adaptable to carers' needs c. The service gives confidence and can be trusted	• Does this service work in partnership with you and the person you care for? Are you fully consulted about caring arrangements? • Did you get full information and a chance to meet staff or visit the service before making any decision? • Is the service flexible enough to meet your needs? • Does the service give you peace of mind? • Does the service ensure that the person you care for has interesting things to do and foster his or her independence? • Does the service treat you and the person you care for with dignity and respect? Is privacy maintained? • Do you get consistent care from one break to the next (for example, is the same care worker involved)? • Does the service meet the person's personal preferences about the way care is provided? • Does the service properly look after clothes and personal possessions?

Table 4.3 (continued)

Dimension	*Standard*	*Quality criteria*	*Feedback from carers*
3. Emotional support	Any service offering emotional support to carers, either on a one-to-one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers	a. Sensitive to individual needs b. Confidential c. Offers continuity d. Accessible to all carers	• Does this service give you a chance to talk over things in a safe and confidential way (for example, in a group or with a counsellor)? • If you don't get a chance to talk things over in a group or with a counsellor, is this something you would like? • Is there a support group run by carers? • Have you had the opportunity to have a support group run by carers? • Do you get counselling from the service? • Are you happy with the confidentiality of the support service? • In general, how satisfied are you with the emotional support you get from this service?
4. Support to care and maintain carer's own health	Any service that supports carers to care and to maintain their own health and well-being by offering training, health promotion and personal development opportunities and is responsive to individual needs	a. Full information about opportunities available b. Range and choice of opportunities c. Appropriate to needs and circumstances d. Support to participate	• Has the service given you information about ways you can learn more about how to look after your own health and well-being (for example, training courses)? • Have you taken up any of these opportunities (for example, been on a course)? • How relevant is the local training or guidance to your own needs? • Do you get the help and support you need (for example, someone to provide care, help with transport) to get to planning meetings and training courses?

Table 4.3 (continued)

Dimension	*Standard*	*Quality criteria*	*Feedback from carers*
5. Having a voice	Any service that supports carers to have a voice as an individual and/or collectively, is accessible to all carers and can act in an independent way	a. Supporting hidden carers b. Supporting carers to have a voice c. Supporting carers to have a collective voice	• Does the service help you to speak up about what is important for you as a carer? • Are you part of a group of carers who have a say about services? • How satisfied are you with the arrangements to help you speak up, either as an individual or in a group? • Do you get help or support to take part in meetings, planning sessions and training (for example, help with transport, someone to look after the person you care for)? • Do you get information about planning meetings and training in a form you can understand? • Have you ever been involved in monitoring the way health or social services support carers? • Do you thinks services listen to what you have to say and take notice? • Do services tell you how they will respond to feedback from carers? • Do you have the chance to meet carers from other places to hear their views and share ideas?

Tasks and issues

As already described, Blunden's guide and checklists are based on a detailed literature review and a thoroughgoing process of consultation with a range of key stakeholders. Arguably, Blunden's framework has both construct and content validity for assessing carers' views on the quality of service support. Consequently, there would seem to be little point in repeating the exercise to identify service quality issues relevant to carers; nor can Blunden's recommendations be lightly dismissed. It is clear, for example, that carers' views on the quality of the service support they receive encompass several dimensions, and Blunden's framework provides a firm indication of how these should be defined and measured. Moreover, it appears to be manageable and easily applied in a research context as well as in practice settings.

However, it is apparent from even a cursory reading of Table 4.3 that some of the suggestions for obtaining feedback from carers – both question wording and response categories – require further development and testing before they could be used in carer satisfaction surveys. Some progress along these lines has already occurred as several local authorities and local carer support projects have conducted surveys of carers' views using Blunden's framework. The time is ripe for a review of these surveys and the questionnaires used. We need to know how these instruments performed in practice, and evaluate the usefulness of the data obtained, before a definitive format could be rolled out nationally. Indeed, such a review might inform a further round of evaluation in the field, including cognitive testing of question content and format (Qureshi and Rowlands, 2004).

Nicholas (2001) has also developed a 'Carer's Feedback' form, as part of the SPRU Outcomes Programme, to obtain carers' views about the help provided by social services following assessment or review. It covers carers' views in relation to the impact of services and support on their quality of life, their caring responsibilities, and the way in which help was provided. Although not intended as a survey instrument, the content of this form has been well researched and should inform the development a carers' satisfaction questionnaire. The relevant sections are summarised here in Annex B.

It is also apparent from Table 4.3 that Blunden's framework does not address explicitly the quality of carers' assessments for services or direct payments, or quality issues relevant to direct payments. It will be essential to incorporate carers' views about direct payments because they are considered to play a key role in delivering choice and independence (Department of Health, 2005). Carers' views on direct payments might also be expected to reflect their experience of service delivery and process outcomes.

An earlier review of carers' services argued that although carers' assessments are themselves not a service to carers, they form a substantial part of PSS output (Hirst, 2004). 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 (Banks and Cheeseman, 1998b). Many of the criteria in Blunden’s framework that relate to information, emotional support, and having a voice, relate to the quality of carers’ assessments. Relevant quality criteria might include: confidential and comprehensive review of carers’ needs, circumstances and choices, recognition and respect for the carer’s role and responsibilities, full consideration of the carer’s ability and willingness to carry on providing care, having a permanent record of the assessment and an opportunity to discuss its conclusions.

A novel approach to the measurement of carer satisfaction with the needs assessment of the cared for person has recently been pioneered in Scotland (Infusion Co-operative Limited, 2005). This involved the development and testing of a carers’ questionnaire, which covered preparation for the assessment meeting and the conduct of the meeting itself. Key quality issues for the carer included: being ready for and informed about the assessment process, being recognised as the carer and treated with respect, being included in the assessment discussion and having their perspective and caring responsibilities taken into account. This questionnaire might be adapted to tap carers’ views and experiences of the assessment of their own support needs.

At the time of writing, examples of questionnaires used in carer satisfaction surveys, or that might inform such surveys, are being collected with a view to providing a knowledge base for further development and testing.

References

Audit Commission (2004) *Support for Carers of Older People*, Audit Commission, London.

Banks, P. and Cheeseman, C. (1998a) *The Carers Compass: Directions for improving support to carers*, King’s Fund, London.

Banks, P. and Cheeseman, C. (1998b) *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.

Department of Health (1999) *Caring About Carers: A national strategy for carers*, Department of Health, London.

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.

Department of Health (2005) *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*, Department of Health, London.

Grundy, E., Ahlburg, D., Mohamed, A., Breeze, E. and Sloggett, A. (1999) *Disability in Great Britain: Results from the 1996/97 disability follow-up to the family resources survey*, Department of Social Security Research Report No. 94, Corporate Document Services, Leeds.

Hepworth, D. (2003) Assessment and support for South Asian carers, *Research Works*, Social Policy Research Unit, University of York, York.

Hepworth, D. (2005) Asian carers’ perceptions of care assessment and support in the community, *British Journal of Social Work*, 35, 337-53.

Hirst, M. (2004) Measuring personal social services outcomes: Services for carers, Working Paper No. 2044, Social Policy Research Unit, University of York. York.

Infusion Co-operative Limited (2005) *Development of Tools to Measure Service User and Carer Satisfaction with Single Shared Assessment*, Scottish Executive, Edinburgh.

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

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.

Nolan, M., Grant, G., Keady, J. (1996) *Understanding Family Care: A multi-dimensional model of caring and coping*, Open University Press, Buckingham.

Nolan, M., Grant, G. and Keady, J. (1998) *Assessing the Needs of Family Carers: A guide for practitioners*, Pavilion Publishing, Brighton.

Nolan, M., Lundh, U., Grant, G. and Keady, J. (eds) (2003) *Partnerships in Family Care*, Open University Press, Buckingham.

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

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

Qureshi, H. and Rowlands, O. (2004) User satisfaction surveys and cognitive question testing in the public sector: The case of personal social services in England, *International Journal of Social Research Methodology*, 7, 273-87.

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.

Annex A Risk assessment of caring roles

Critical risk to sustainability of the caring role arises when:

- their life may be threatened;
- major health problems have developed or will develop;
- there is, or will be, an extensive loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- there is, or will be, an inability to look after their own domestic needs and other daily routines while sustaining their caring role;
- involvement in employment or other responsibilities is, or will be, at risk;
- many significant social support systems and relationships are, or will be, at risk.

Substantial risk to sustainability of the caring role arises when:

- significant health problems have developed or will develop;
- there is, or will be, some significant loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- there is, or will be, an inability to look after some of their own domestic needs and other daily routines while sustaining their caring role;
- involvement in some significant aspects of employment or other responsibilities is, or will be, at risk;
- some significant social support systems and relationships are, or will be, at risk.

Moderate risk to sustainability of the caring role arises when:

- there is, or will be, some loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- there is, or will be, some inability to look after their own domestic needs and other daily routines while sustaining their caring role;
- several social support systems and relationships are, or will be, at risk.

Low risk to sustainability of the caring role arises when:

- there is, or will be, some inability to carry out one or two domestic tasks while sustaining their caring role;
- one or two social support systems and relationships are, or will be, at risk.
  Source: Department of Health (2001b, pp. 26-7).

Annex B Carers’ feedback form

A. Quality of life			
As a result of the services/support received … (This may include home care, equipment in the home, day care, sitting service, respite breaks, carers’ group, someone to talk to/emotional support, and other help)	*Has/have greatly improved*	*Has/have improved a little*	*Has/have not changed*
1. My physical health or well-being (including sleep, rest, exercise, etc.)			
2. My emotional or mental health (e.g. feelings of stress, anxiety, depression)			
3. Time to myself and to have a life of my own (e.g. work, studies, interests, other commitments)			
4. My relationships (with the person I care for or other people)			
5. My financial or material circumstances (e.g. income, housing)			
6. My feeling of control over my life (e.g. my ability to make plans for myself and stick to them)			
7. My peace of mind (being less worried about the well-being of the person I care for)			
B. Managing caring			
The services/support received …	*Helped a lot with this*	*Helped a little with this*	*Made no difference*
1. I feel more confident and knowledgeable in what I do as a carer			
2. I gain a sense of satisfaction or achievement in caring			
3. My caring responsibilities have been reduced or shared (to an acceptable level)			
4. I feel I’m not alone in caring – I have someone to talk to if needed			
5. I am able to manage the physical/practical caring tasks			
Continued on next page			

C. How services and support are provided			
These questions are about the way services/support are provided, and how they affect you.	*Always*	*Mostly*	*Not at all*
1. Are you and the person you care for treated with respect?			
2. Is your expertise as a carer recognised?			
3. Do you feel you have a say in the way the service/support is provided?			
4. Is the service/support provided in ways that fit in with your life and routines?			
5. Do you get on with the staff you have contact with? (e.g. Do you feel at ease with them? Are they approachable and helpful? Are you able to understand and communicate with them?)			
6. Do you feel the service(s)/support provided is (are) value for money?			

Source: Nicholas (2001)