King's Fund

# Quality Local Carer Support Services

## Part I
What Carers Say About Quality:
A Review of the Literature

## Part II
Work in Progress on Quality Services

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# Contents

## Part I

# What Carers Say About Quality - A Review of the Literature

## Introduction

1.1 There is now a considerable body of evidence about what matters to carers from day to day. Above all, they look for an ordinary life. This in turn implies being able to choose what to do and where to live, and having a say in the services they receive -being treated as partners rather than clients *(a)*. Carers place a strong emphasis upon personal dignity, respect and self-esteem for themselves and those they care for *(b)*. They want the professionals they come in contact with to share these values and also to be knowledgeable and skilled *(c)*. In addition, they expect services to make a positive difference to their lives by offering them information, emotional support, opportunities for a break, training and support to care, recognition and financial security *(d)*.

1.2 When asked in more detail about the services they would like, carers have made many thoughtful observations both about the principles that should underpin services and about how these should be translated into practice. This literature review seeks to gather these observations together and present them in an accessible format. Carers' messages about services are presented in a series of charts under key outcomes - being informed, time off, and so on. In the first column of each chart appear the principles or quality issues which carers have identified as important in services which relate to the headline outcome. Carers' detailed interpretations of what these issues mean in practice are presented in the second column, and the references to the literature in the third. It is important to note that only those sources which directly report the views of carers have been used. Inevitably, the literature is uneven in its coverage of different kinds of provision. For example, a great deal of attention has been paid to information giving and various forms of respite care; in comparison, there are few sources on services promoting financial security for carers or offering them training to care.

### References (introduction only)

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b) Unell J., Bagshaw H., *Examining outcomes in community care. Report on focus groups for the Social Policy Research Unit,* 1998 Unpublished report, Social Policy Research Unit, University of York.

c) Harding T., and Beresford P., *The standards we expect. What service users and carers want from social services workers,* 1996, National Institute for Social Work

d) Banks P., Cheeseman C., *Taking Action to Support Carers. A Carers Impact guide for commissioners and service managers* , 1999, Carers Impact, King's Fund.

## 1.3 Being informed

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Comprehensiveness** | • Much more medical and practical information than is usually given at present: particularly, information about the condition of the person cared for and its progression, including indicators of further deterioration and possible outcomes; information about services and equipment available to help; professional contacts; information about benefits and other forms of financial support. | 5, 11, 14, 17, 18, 21, 41, 47, 48 |
| | • Information also to be given about personal, social, lifestyle options for the person cared for, avoiding over- dominance of medical perspective. | 20, 23 |
| | • Cross-referencing by professionals to other sources of information and support (plus a willingness to provide referrals). | 20, 41 |
| | • Local information bases to be enlarged to include non-local options such as the Independent Living Fund | 23 |
| | • Internet access for carers | 22 |
| | • Local carers information packs to include contact points and directories of organisations | 5 |
| | • A willingness on the part of professionals to discuss sensitive information about the person cared for, negotiating confidentiality protocols where required | 23, 41 |
| | • Independent lines of communication from professionals to user and carer | 5 |
| | • A less defensive attitude on the part of professionals to handing out information, particularly where there are cost implications for service provision | 16, 23, 24 |
| | • Free availability to employees of information on flexible working options | 26 |
| | • Early diagnosis of dementia and appropriate referral to specialist services. | 44 |

## 1.3 Being informed (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Accessibility & Responsiveness** | • A more proactive approach to information-giving. Information should be offered when needed; the carer should not always need to seek it out | 5, 16, 24 |
| | • Information available in a range of minority languages, supplemented by verbal messages because of literacy problems . | 15 |
| | • A mix of methods of information-giving: e.g. `one stop shops', face-to face discussions, leaflets, videos, audio-cassettes. | 5, 15, 24, 48 |
| | • Temples, community meeting places, Asian TV / radio programmes good channels for reaching Asian carers. | 15 |
| | • Taking the information to the carer wherever possible. Outreach and awareness -raising particularly important for minority ethnic carers because of the stigma often attached to disability | 24, 25 |
| | • More triggers within the system. such as the awarding of Disability Living Allowance, to ensure that carers are identified and presented with information | 22 |
| | • Opportunities to talk to professionals from same ethnic group | 24 |
| | • Plain language, no jargon | 5, 21, 24 |
| **Timeliness** | • Information to be offered in advance of key transitions – e.g. hospital to home - to enable carer to be prepared. | 5 |
| | • Information always to be provided as early as possible but also to be `paced' according to carer's capacity to absorb and use it. It may need to be repeated as circumstances change | 5, 20, 17, 44 |
| | • Systematic monitoring and recording of information given to individual carers | 5 |
| | • Helpline for dispensing urgently-needed information, for example to carers of people with mental health problems during a crisis | 14 |

## 1.3 Being informed (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Expertise** | • Information that is accurate, reliable, consistent and up-to-date. | 45 |
| | • Access to someone who 'knows the system' and can give the carer a reliable overview of what is available. | 16 |
| | • Professional support and guidance in sifting information and assessing its relevance. | 22 |
| | • Greater range and depth of information available from GPs | 23, 41 |
| | • Detailed information from medical staff on medication regimes - particularly an issue for carers of people with mental health problems where regimes change frequently. | 20, 47 |
| | • Independent advice, particularly for parent carers who have complex decisions to take about the care and education of their children | |
| **Partnership** | • information-giving to be part of a continuing, equal dialogue between professionals and carers. | 17 |
| **Empowerment** | • Advice and advocacy services that go beyond the straightforward provision of information - e.g. help in identifying appropriate benefits and filling in forms; support in dealing with statutory agencies. | 22 |
| | • Someone to act as a personal advocate, explaining each aspect of caring role and helping to access available help. | 24 |
| | • Choice of models for advocacy services - e.g. 'one stop shop', telephone hotline. | |
| | • Access to interpreters for black and minority ethnic carers | 40 |
| | • Partnerships between statutory services and black community organisations in order to provide effective advocacy for black and minority ethnic carers. | 22, 24 |

## 1.4 Time Off

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Appropriateness** | • Residential respite care which is suitable for the age group, lifestyle, ethnicity and personal needs of the person cared for. For example, enabling younger people with disabilities to be with their peers, people to be placed with others from similar ethnic/cultural backgrounds, to be in a non-smoking environment if preferred . | 1, 2, 3, 13, 15, 19, 22, 25, 40 |
| | • Friendly, homely atmosphere with personalised care | 1, 23 |
| | • Where respite is given at home, sensitive matching of staff/volunteers and families according to language, culture and background. | 2, 13, 25 |
| | • Food which is acceptable to people from different religions and cultures | 12, 2, 13 |
| | • Hair and skin care appropriate to particular ethnic groups | 12 |
| | • A stimulating environment for people with communication difficulties | 22 |
| **Availability** | • More provision, particularly for carers of people who are poorly served at present, such as adults with learning disabilities, children with severe behavioural problems; also for carers in minority ethnic groups who tend to have a `younger' care profile and are typically balancing caring responsibilities with childcare and family commitments. | 1, 13, 15, 19, 20, 21, 28 |
| | • local provision, avoiding exhausting journeys | |
| | • reasonable cost | 10, 15 |
| | • satisfactory transport arrangements | 17 |
| | • carers subjective experiences (e.g. of stress) to be taken into account when assessing amount of respite needed.) | 1, 45 |
| | • Minimum basic respite available to all carers | 15, 18 |

## 1.4 Time Off (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| Choice | Options for breaks which users and carers can take together | 45 |
| | Offer of non-hospital settings for residential respite for people with mental health problems | 10 |
| | More respite options using a variety of models for all carers and particularly for ethnic minority carers who may prefer non-institutional care. | 3, 46 |
| High Standards of Personal Care | Keeping track of clothes and personal possessions; | 25 |
| | Paying close attention to personal hygiene | 19 |
| | Following the cared-for person's preferred methods for lifting, feeding etc, sharing the knowledge of the carer | 20 |
| | Staff appropriately trained to cope with the behavioural and physical needs of the cared-for person. | 11 |
| | Being made welcome on admission | 3, 19, 23 |
| | Regular breaks agreed and guaranteed | 1, 46 |
| | Dependable transport | 45 |
| | Consistent quality of care from one break to the next | 1, 45 |
| | Same sitter each time - and on time. | 42 |
| | Being able to plan ahead | 45 |
| Flexibility | Readiness to fit respite care around the needs of the carer, for example by allowing mid-week starts & breaks of non-standard length - a particular issue for Black and minority ethnic carers who may need to take long journeys abroad. | 1, 2, 15, 17, 21 |
| | Back-up arrangements for care in a crisis | 9, 46, 48 |
| | Sitting services provided at times which meet the social needs of the carer. | 24 |
| | Flexibility around time-limits for sitting services- the need to obsessively clock-watch undermines the value of the break to the carer. | 9 |
| | Minimum bureaucracy in arranging respite breaks | 8 |

## 1.4 Time Off (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Timeliness** | • Respite to be made available at point of diagnosis for people with conditions such as dementia, rather than when things become desperate | 15 |
| **Partnership** | • Respect for the carer and the caring relationship | 9, 11, 15 |
|  | • Staff/volunteers who recognise and consult the carer's opinions and expert knowledge of the person cared for. | 11 |
|  | • Where a family placement is the best option, carer to be given full information about the placement in advance. | 11 |
|  | • Opportunities for carers to discuss role of temporary caregivers in relation to their own. | 9 |
|  | • Staff in residential facilities recognising carer's need to visit. | 46 |

## 1.5 Emotional support

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Sensitivity to Carers' Emotional Needs** | • Carers being recognised and valued for their work. | 18 |
| | • Recognition by professionals of the stresses of caring. | 17 |
| | • Carers emotional needs being seen as separate from those of the cared-for person. | 17 |
| | • Help with acknowledging and dealing with emotions such as guilt | 18 |
| | • Help with negotiating limits to caring responsibilities | 18 |
| | • Someone to confide in | 18 |
| | • More active listening on the part of professionals, with appropriate training to enhance their skills. | 24 |
| | • Opportunities to talk over important decisions/ work through complex issues, such as permanent care. | 22, 23 |
| **Continuity** | • Continuing relationship with professionals –such as specialist nurses- beyond permanent care and bereavement. | 6 |
| | • Where person cared for has long-term mental illness, continuing support by designated worker. | 14 |
| | • Special support groups for recently bereaved carers. | 37 |
| **Accessibility** | • Need for emotional support should be recognised as a specific requirement for carers and should be offered routinely. | 23 |
| | • For carers using telephone helplines, access to trained counsellors where appropriate. | 39 |
| | • Locally accessible support groups. | 19 |
| | • Better signposting of new carers to carers groups and courses; opportunities for housebound carers to contact others. | 19 |

## 1.5 Emotional support (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Accessibility (cont.)** | • Venues and times of groups a particularly important issue for black and minority ethnic carers, i.e. places where they feel safe, and times that take into account the long working hours in communities. | 2 |
| | • Asian carers support groups for those caring for people with mental health problems, to prevent strain, illness and isolation among carers and to improve understanding of needs of person cared for. | 36 |
| | • Support for the development of carer-led black carers groups, perhaps by funding black community groups to facilitate them. | 40 |
| | • Appropriate professional resourcing for carers groups, without taking them over, e.g. help with publicity, provision of sitting services so that carers can attend. | 19, 35, 40 |

## 1.6 Training and support to care

| Quality issue | What carers say this means in practice | References |
|---|---|---|
| **Appropriateness to Needs and Circumstances** | • Expert practical training in areas such as lifting, management of catheters, incontinence care.<br>• *But* requirements of physical care post-hospital discharge should be realistic and within the carer's limits.<br>• Training in managing behaviour problems - e.g. how to respond when someone becomes violent.<br>• Professionals available to offer expert instruction in the home, taking adequate time and repeating information as required. | 5, 18, 22, 48<br>41, 48<br>14<br>20 |
| **Responsiveness in a Crisis** | • Emergency advice on coping with someone who is violent in the home - directly, without being passed around between professionals.<br>• 24 hour helpline for carers of people with mental health problems.<br>• Reliable cover in a crisis<br>• That people coming into the home in a crisis are known and trusted by the person cared for. | 17<br>14<br>19<br>19 |

# 1.7 Financial Security

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Adequacy of Income** | • Financial assistance so that carers can buy help that enables them to continue caring. | 31, 48 |
| | • National review of benefits available to carers, with the intention of removing financial barriers and disincentives to work. | 34, 38 |
| | • Efficient processing of benefit claims. | 24 |
| | • Streamlining of financial/benefit assessment forms - common form for all public bodies | 34, 48 |
| | • Enhanced income levels to compensate for additional costs of caring and restrictions on lifestyle | 19, 48 |
| | • Help with processing insurance claims when the person cared for is prone to destructive behaviour. | 14 |
| **Adequacy of Information** | • Information about locally-based services, benefits and employment policies, including written and personal guidance. | 19, 34 |
| | • Freely available information from employers about carer-friendly policies in the workplace and flexible working options. | 26 |
| | • Someone to talk to about pension rights and legal status in order to inform choices - e.g. about giving up work to care. | 22 |
| | • Someone to talk to about financial consequences of placing a relative in permanent care, including means-tested fees and costs of travel to visit. | 32 |
| | • Professionals making a point of asking how carers are coping financially, offering help before a crisis. | 34 |

## 1.7 Financial Security (cont.)

| Quality issue for carers | What carers say this means in practice | References |
|---|---|---|
| **Awareness and Responsiveness on the Part of Employers** | • Range of flexible working options, including flexitime, part-time working, temporary reduction in hours, compassionate leave, discretionary leave, annual leave bookable at short notice, special annual leave provision, working from home. | 26 |
| | • Formal carer-friendly policies to support these options, making flexibility at work an entitlement | 28 |
| | • No loss of status or job security through working flexibly. | 27 |
| | • Time off for emergencies and for appointments | 27 |
| | • Access to a telephone at work for keeping in touch with home | 28 |
| | • Opportunities for career breaks to care, with reinstatement at same grade upon return. | 27, 29 |
| **Flexibility on the Part of Services in Relation to Carers in Employment** | • More rapid response from Social Services when support needed, avoiding time-consuming, bureaucratic arrangements. | 28 |
| | • More flexible and generous approach to service provision to enable carers to take up and retain jobs and training opportunities. | 19 |
| | • Better childcare provision for disabled children, especially older children. | 34 |
| | • Improved co-ordination between employers and service providers in the community in order to support families in combining work and care. | 34 |
| | • Hospitals and other healthcare providers to take into account carers' hours of work , with opportunities for appointments outside the working day. | 34 |
| | • Opportunities for carers to purchase agreed allocation of care services independently in order to tailor services to individual needs. | 19, 48 |
| | • Recognition of carers' needs for time to relax and socialise outside work - e.g. through provision of sitting services at appropriate times. | 28 |

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## Part II

# An Overview of Current Work Relevant to Developing Quality Standards in Local Support Services For Carers

In order to inform the Steering Group's thinking about the development of quality standards for local carers support services, this paper has attempted:

- to outline briefly the general context for work on quality standards in service provision;
- to highlight some of the issues and problems in defining quality standards;
- to consider national work which is of relevance to quality standards in local support services for carers;
- to present the findings of a survey of local organisations on work in progress in defining and implementing standards for carers support services.

## 1 The push for quality standards

1.1 In a mixed economy of care, the issue of how to guarantee a similar quality of service to all users and carers has become ever more pressing. As evidence has grown of the consistency of people's preferred outcomes and their expectations of services, there has been a more acute awareness of gross inconsistencies in the provision of services within and between service sectors and in different geographical locations. In the aptly entitled report, *'A Matter of Chance for Carers?'*, the Social Services Inspectorate notes that *'Support depends far more on where carers live and who they are in contact with in social services than on what they need.'* (1) The setting of quality standards for services has increasingly been viewed as a tool for ironing out these inappropriate variations. The National Strategy for Carers (2) has identified a need for standards which apply to all carer support services in order to ensure quality for individual carers. This echoes the current push for standards in many other areas of health and social care and indeed across the whole arena of statutory and voluntary activity. Recent examples can be found in the government's charter for long-term care, 'You and Your Services' (3) which advocates standards relating to key aspects of provision, and in the Compact on Relations between Government and the Voluntary and Community Sectors (4) which calls upon voluntary and community organisations to develop appropriate quality standards. Explicit sets of standards have been developed by the Health Advisory Service 2000 for health and social care services for older people (5) and mental health service for older people (6) and by the Commission for Racial Equality in relation to racial equality in local government (7).

1.2 Within the voluntary sector, the National Council for Voluntary Organisations has responded to the Deakin Commission's (8) call for a clear understanding of standards and an acceptance of performance measures by establishing a Quality Standards Task Group. Although the Task Group has since moved away from the notion of sector-wide standards or a universal quality system, it has recommended a set of quality principles for all voluntary organisations and is currently exploring the use of the Excellence Model as an over-arching quality framework for the sector. (9)

## 2 But what is a quality standard?

2.1 For such a popular concept, the quality standard remains strangely elusive. Definitions abound (some are given below) but in practice, as the results of the local survey presented below suggest, there is considerable confusion about what a standard is and how it can be applied and measured. The problem seems partly to lie in the labyrinthine vocabulary of qualityspeak in which the unwary can too easily lose their way in the twists of meaning that separate different concepts. More fundamental, however, is the difficulty of making explicit the complex and often intangible elements which make up a good service. There are temptations to measure the measurable rather than the meaningful, to produce elaborate checklists which have no hope of systematic appraisal, and to base standards upon the intuitions of staff rather than the direct experience of users and carers.

2.2 Formats for expressing standards vary. They may be simple aspirational statements or quantitative targets. But an increasingly common approach is to divide the standards (also called principles and guidelines in some formulations) into two elements. The first part is broadly a statement of what must be achieved; the second defines what must be done, or put in place, in order to achieve it. The latter element is often described as a set of measures or criteria. Sometimes, as in the PQASSO quality assurance system, the measures are broken down into different levels of achievement, containing the notion of progression in the development of quality from a basic standard. In other approaches, as in the guidelines provided by the Telephone Helplines Association, they are divided into what is essential and what is `worth considering'. In yet others, as in the Health Advisory Service 2000 standards and the Alzheimer's Disease Society 's Quality Care Service Standards (discussed further below) they are not differentiated according to level or priority.

2.3 Although this approach to standard-setting has the considerable advantages of clarity and conciseness, its value critically depends upon:

- the standards set actually expressing what is important to users and carers;
- the criteria or measures bearing a demonstrable relationship to the overall statement. There are dangers of assuming that the chosen criteria will *necessarily* lead to the identified goal or outcome, when independent validation may in fact be necessary to show this.

- the standards and the criteria/measures being exposed to continuous scrutiny so that they keep pace with changing practice and with the expectations of users and carers.

## 3 Relevant national work

3.1 Generic quality systems and standards have been (or are being) developed by specialist national organisations in the fields of information, advice and counselling. It is likely that some of these can be translated to carers support services which perform these functions - for example, the Carers National Association has adopted the guidelines for good practice published by the Telephone Helplines Association. The Federation of Independent Advice Centres has rewritten the PQASSO quality assurance system for advice work, and the British Association of Counselling has produced a code of practice and ethics which is widely used in the field. Another recent initiative of note is a quality task force of organisations which dispense legal advice, currently meeting under the aegis of the Lord Chancellors Department with a view to agreeing a standard set of quality criteria which can form the basis of a Community Legal Service quality mark.

3.2 Some of the standards already identified by the Health Advisory Service 2000 in relation to services for older people have a direct bearing upon the work of the Steering Group. In particular, standards and criteria have been developed for respite care and for information for users and carers (an example is reproduced below).

3.3 Key national organisations with a remit for supporting carers have recognised the need for promoting a consistent quality of carer support at local level. The desire of local service purchasers for a quality guarantee has provided an added impetus. In the past, headquarters initiatives on quality have proved contentious among local member organisations which tend to be jealous of their expertise and independence, resisting any criticism implied by the need for standards. More recently, however, local schemes have become more receptive to the advantages of a unified approach to quality in their dealings with local authorities and also within their own organisations - often because it provides an opportunity to bring trustees or committee members up to speed.

3.4 Crossroads, the Princess Royal Trust for Carers and the Azheimer's Disease Society have gone down slightly different paths in their pursuit of consistency and quality, but there are a number of common issues. The first two have decided to adopt quality assurance systems which are organisation-wide. This means that quality standards for services sit within a more general framework of organisational standards. Both PRTC and Crossroads have had a longstanding commitment to guaranteeing quality throughout their organisations, nationally and locally. More recently, both have decided to adapt the PQASSO quality assurance system to their particular needs. The PRTC has produced a manual to support carers centres in their use of PQASSO for promoting organisational standards and has convened a working group of carers centre managers to provide guidance on service standards. Crossroads has gone for a thorough re-working of PQASSO in order to adapt it to the structure, functions and language of the organisation. In the resulting version, CROQUET, service standards have been incorporated alongside organisational standards, although in a slightly different format. Whereas the organisational standards are each linked to three levels of achievement in the style of PQASSO, the standards for direct services to carers are presented in a straightforward list, echoing the view of Crossroads that good quality provision for carers should be in place at the outset.

3.5 The Alzheimer's Disease Society has expressed its commitment to quality by prioritising service standards within its quality assurance framework and has developed a detailed system for specifying and measuring standards within care services, for both users and carers. Each aspect of client care - for example, referrals, the physical setting, meals and refreshments, health and safety -is assigned a required outcome followed by a series of points which indicate what needs to be in place in order for this be achieved. An identical format is used in setting standards for staffing and management arrangements linked to client care. The Society is looking at ways of addressing quality in its other services.

# 4 The findings of a survey of local organisations

## 4.1 The survey and the response

4.1.1 A brief postal questionnaire was circulated through various service networks - statutory, voluntary and private. Since the sampling was entirely opportunistic, it was not possible to estimate a percentage return. 133 completed questionnaires were received; another 100 organisations indicated their interest in the work on quality standards for carers and asked to be kept informed.

**The 133 completed responses came from:**

73 statutory organisations

53 voluntary organisations receiving funding

6 self supporting voluntary groups

1 private/commercial organisation

4.1.2 Social Services supplied 25 of the statutory sector responses; 44 came from Health and four from joint Health/Social Services bodies. The Health responses were particularly diverse. While NHS Trusts formed the clear majority (33), responses were also received from individual hospitals, a mental health team, health authorities, a primary care group and a health centre. No response was received from a GP but this may well reflect the mode of circulation of the questionnaires within and between major organisations. The single private/commercial response was sent by a private nursing/home care organisation.

4.1.3 Among the voluntary sector responses, carer-specific organisations accounted for a clear majority (37). These included carers centres, carers support projects, branches of Crossroads and Carers National Association, and an independent local carers association. Other responses came from organisations providing specific services (such as a voluntary day centre and a hospice), and from those whose activities related to a particular condition (such as the Alzheimer's Disease Society, National Schizophrenia Fellowship) or social group (MENCAP, Age Concern). Infrastructure organisations (a Council for Voluntary Service and a Rural Community Council) were also included.

4.1.4 While the sample cannot be claimed to be representative, it contains a good cross-section of organisations currently providing support services to carers. It is therefore adequate for the purpose of giving an impression of the 'state of play' within the field with regard to the development and implementation of quality standards.

## 4.2 The services being provided for carers

4.2.1 Information and advice-giving to carers was the most widespread service activity among the respondents. Substantial numbers were also involved in training/advice about caring, emotional support/counselling, and providing carers with a break. At the other end of the range came employment support for carers, offered only by a small minority. It was clear from many of the statutory sector responses that not all the services identified were being provided directly; in many cases, there was a mix of direct provision and services delivered via organisations in the voluntary and private sectors by means of contracts or service agreements.

| Service | Number offering (N=133) | % offering |
|---|---|---|
| Information giving and advice | 119 | 89 |
| Training and advice to care | 85 | 64 |
| Emotional support and counselling | 95 | 71 |
| Employment support | 10 | 8 |
| Translation / interpretation | 42 | 32 |
| Services which provide a break | 82 | 62 |
| Advocacy | 55 | 41 |
| Money / benefits advice | 52 | 39 |
| Health services directed at carers | 23 | 17 |
| Self help groups | 55 | 41 |

4.2.2 Additional carer-directed activities identified by respondents included projects for young carers, befriending schemes, outings and social evenings, escort provision, domiciliary care, therapies, relaxation and nursing care.

4.2.3 Under the heading of 'services which provide a break', respondents were asked to identify specific kinds. This showed that while they were active across the whole range of respite provision, there was a preponderance of services in people's own homes, day provision and residential breaks:

| Services which provide a break | Number providing (N=82) | % providing |
|---|---|---|
| In people's own homes | 55 | 67 |
| Holidays | 16 | 20 |
| Residential care | 40 | 49 |
| Hospital | 6 | 7 |
| Day opportunities | 51 | 62 |
| Leisure or learning opportunities | 28 | 34 |
| Shared care in families | 19 | 23 |

## 5 Setting quality standards

5.1 90% of respondents said that their organisation had set standards for the carer support services which it provided. Among these positive responses, there were many who signalled good intentions rather than established practice by adding phrases such as: '*We're working on it'*; *'Early days yet'*; *'They're being developed'*. Similarly, several who said that standards had not been set claimed that this was a priority for the future. There was a general impression that organisations in all sectors were at the very early stages of thinking and practice in their work on standards for carers services.

5.2 In considering the more detailed information which the survey provided on standards, the responses of statutory and independent organisations are considered separately. ('Independent' is used here as a term of convenience to cover funded and unfunded voluntary bodies plus the single commercial provider).

## 5.3 Statutory organisations

5.3.1 Key points to emerge were:

- There was a widespread concern to meet the needs and expectations of carers by providing services of good quality, both within mainstream provision and among carer-centred initiatives;
- At the same time, it was difficult to ascertain how far the sector had progressed in defining quality in carers services and developing appropriate means of measurement and monitoring. Very few respondents offered explicit examples of quality standards for carer support.
- Many organisations had embarked on exercises which were designed to embed carers' views and needs into service provision. Carers strategies, action plans, charters , policy guidelines, statements of commitment and operational checklists were submitted as examples. While undoubtedly valuable tools for shaping a more carer-centred approach to services, these were usually directed towards improving the repertoire of carer support rather than specifying detailed standards for the delivery of services.
- In undertaking such exercises, organisations were usually careful to consult and involve carers, although some used carers organisations as a proxy. Methods of consultation varied. Carers were often involved as members of working groups but there were examples of research-based investigations of carers' needs by means of focus groups and feedback surveys.
- For directly-provided services, the needs of carers were often incorporated into general quality statements, alongside those of users, staff and other stakeholders. Thus although the interests of carers were recognised, there seemed to be little differentiation between their needs and those of other groups. Indeed, some respondents saw such differentiation as unhelpful, for example:

  > *"Our organisation does not differentiate between users and carers when we are considering setting standards. We have tended to emphasise the links in the user/carer relationship, while making sure that the rights of carers to separate assessments, relief from caring responsibilities etc. are respected".*

  The result, however, was often that references to carers needs were brief, general and unspecific. There were some positive exceptions where the response to carers had been carefully considered and some clear and detailed standards developed (examples are given below).

- Many respondents said that their organisation built carer-related specifications into contracts and service agreements with independent providers for services such as respite care and domiciliary care and also for carer support services, such as carers centres. In some cases, carers had been consulted or involved in defining the specifications- for example, one Social Services Department had involved carers in drawing up specifications for four home care block contracts. In general, however, it is difficult from the evidence supplied to assess how far service specifications translate into detailed quality standards. The few examples submitted by respondents suggest that specifications often relate principally to the amounts and kinds of services that are to be provided. While these are important aspects of quality, they do not encompass vital aspects arising from the processes of service delivery. There were, however, encouraging signs of partnerships with providing agencies to define mutually helpful and detailed standards. For example, one organisation had used the quality manual produced by the Princess Royal Trust for Carers in working with a carers centre to negotiate the specifications of a service contract.

## 5.4 Independent organisations

5.4.1 The voluntary sector responses provided proportionately more examples of standards linked to carer-specific services. Although these were still submitted by a small minority, the overall impression was that voluntary organisations were further ahead than those in the statutory sector in identifying carers as a distinctive user group and in grappling with the issues of defining and measuring quality. Most of the standards (see examples below) were simple statements describing required attributes of services, but some organisations had begun to develop a comprehensive and detailed analysis of their services in terms of the standards required and the means of achieving them.

5.4.2 This more developed picture undoubtedly reflects the nature of the organisations represented, many of them carers organisations and others having a well-defined carers remit. They were therefore closer to the ground in terms of carer support than most statutory bodies.

5.4.3 For those affiliated to national bodies, policy initiatives and guidance from headquarters organisations appeared to be of great importance in shaping a more systematic approach to quality provision. Local branches of the Alzheimer's Disease Society, Crossroads, and carers centres linked to the Princess Royal Trust for Carers and the Carers National Association referred to national policies and procedures which framed their local practice. They also referred to headquarters-led quality initiatives which had already been implemented or which were about to come on stream – in particular the Care Consortium Quality Service Standards which were introduced by the Alzheimer's Disease Society two years ago, PQASSO (widely used by carers centres) and CROQUET (an adaptation of PQASSO developed by Crossroads). The response from the headquarters of the National Schizophrenia Fellowship indicated that quality standards for carers groups are about to be implemented.

5.4.4 Where specific standards for carer support had not yet been adopted, organisations relied on a range of other mechanisms to guarantee quality in provision. Policies for specific services (such as counselling) and for generally safeguarding the rights of users and carers (for example, equal opportunities and complaints) were referred to by respondents. There was also an emphasis on using properly qualified staff for skilled interventions such as benefits work, counselling and therapy. Some organisations providing counselling did so within the framework provided by the British Association of Counselling Standards. Many organisations also operated to the general standards set by local statutory bodies in contracts and service-level agreements.

5.4.5 Perhaps surprisingly, there appeared to be less emphasis on the formal involvement of carers in the formulation of policies and standards within voluntary organisations. This work was usually carried out by trustees, management committee members and staff working groups. There may, of course, have been carer representation at committee level but there were few references to formal consultation beyond this. The main input from carers came through feed-back mechanisms designed to gauge their satisfaction with the services offered.

5.4.6 The latter appeared thorough and varied, encompassing informal, ad hoc comments, satisfaction questionnaires, regular reviews of services and evaluation reports which included the carer's perspective.

5.4.7 (N.B. The single commercial provider responding to the survey interpreted the term carer as a paid care assistant and referred to minimum standards of employment and training.)

5.4.8 The local survey suggests a patchy and somewhat confused picture. It is clear that quality in service provision for carers is an issue of concern for both statutory and voluntary organisations but that, as yet, there is little consistency or coherence in the development and implementation of quality standards. Those organisations which have begun to move towards more systematic standards are still in the very early stages of this process. An important lead has been taken by national carers organisations in the voluntary sector through organisational quality initiatives which encompass standards for support services, although these have not yet been implemented in the field.

## 6 General points emerging from the overview

6.1 Although there is a growing acceptance, nationally and locally, of the need for quality standards to guarantee consistency in service provision, the development of standards for carers support services is still in its infancy. Within the field, quality standards are frequently assumed to be embedded in organisational policies, codes and procedures rather than being separately identified.

6.2 The format for expressing standards is variable, but it is increasingly common to incorporate a statement of what is to be achieved and a set of criteria or measures describing how this is to be done.

6.3 There are few examples of quality standards specifically designed for carers support services and these are mainly to be found within the voluntary sector where key national organisations have taken a lead on quality. Function-specific standards relevant to carer support have also been developed by specialist organisations in the fields of information, advice and counselling.

# Quality standards:

## Some definitions and observations from the literature

*Standards are simply specific expectations of staff performance described in terms of an activity or outcome against which the performance can be measured. Accompanying a standard will be an indicator or criterion to be achieved in order to measure that performance,* Dickens (10)

*Quality Standard - a predetermined means of measuring the quality of a function or process,* Quality Standards Task Group (9)

*A standard can be defined as something which is:*

- *Agreed and understood by all staff.*
- *Objective and unambiguous.*
- *A commitment that people using the service should always be able to expect.*
- *So clearly defined that it should be obvious to all concerned if the standard is not being met.*
- *Capable of being consistently met. The organisation believes that it has the staffing levels, budgets and other resources capable of meeting the standards,* Lawrie (11).

*Standards can be categorised according to the degree of authority to be attributed to them. There are standards that must be complied with; guidelines that should be followed most of the time; and options that can be freely chosen.* Williamson. (12)

***Standards exist only to be achieved and then redefined. They are only a means to an end.*** Department of Health. (13)

# Examples of standards relevant to the remit of the Steering Group

## a) From national publications

The HAS Advisory Service has written a standard for respite care for older people:

> ***Flexible and planned respite care is available to support older people with chronic health problems and/or physical disabilities, and their carers***

**Criteria**

- A range of respite care services is available in the community, in hospital and in residential care.
- Respite services provide support and relief for informal carers and families looking after older people.
- Flexibility is genuine and aimed at the carer; not the service.
- Charges are not a disincentive
- Respite arrangements are regularly reviewed
- Respite care is part of the ongoing assessment process

A variation on this standard has been written for respite care for older people with mental health problems. Standards have also been developed for information for users, carers and others.

The Telephone Helplines Guidelines for Good Practice cover all aspects of staffing and running a helpline. Under the heading of Information Resources, the following example demonstrates a more open approach to setting standards:

***Do you make sure your information is accurate, up to date and safe?***

*Essential:*

a) Updating information regularly (how often?) and making sure all copies are amended at the same time. If you do not have the resources to do this can you work with helplines/organisations that do?

b) Gathering information directly from organisations or through a reliable source. Be careful to check credentials, to protect callers from dubious organisations ...

c) Dealing with doubts about organisations in your files. This can include anything from reports of poor service to accusations of serious malpractice. It may be helpful to develop a policy on this issue to best protect yourself and callers.

*Worth considering*

d) Noting the source of information and the date you acquired it

e) Having a system for constantly checking and updating factual information, or sharing the work with other organisations.

f) Deleting questionable or inaccessible organisations or noting individuals within them if there are any doubts about their validity.

## b) From the local survey

The following examples are designed to illustrate some of the different approaches demonstrated by the survey towards standard-setting for carer support. Although few organisations offered fully-articulated standards with measures attached, they showed a common concern to pin down the key qualities of the services provided for carers.

A Social Services Department has developed a set of core standards for assessment and care management. While these lie outside the immediate arena of carer support services, the process of developing the standards provides an excellent model for carer involvement. Along with users, frontline staff and managers, carers were encouraged to inform the process by drawing on their own measures of quality. The mechanisms were focus groups and a series of ten development workshops.

Some of the standards generated could be translated to direct support services- for example, those relating to the **promptness and courtesy of responses** and the commitment **to offer full information and involvement at all stages.**

An NHS Hospital Trust has developed a policy for recognising and working with carers. The policy has been developed on the basis of key principles which include:
*Carers - family partners and friends- provide the majority of care in the community. They need to be recognised and account needs to be taken of what they say*

A series of specific requirements then follows, for example:

**The carer will be given the room to explore what they can contribute and what they want to contribute**

*The carers expectations and concerns should be noted. It should be made clear that the carer is welcome to collaborate with staff on the ward. This would mean that the carer is welcome to stay away, to come when they can, to stay in touch by telephone*

A **local branch of the Carers National Association** briefly indicated the following standards:

- Information giving - **accuracy**
- Emotional support - **sympathy and a listening ear**
- Advocacy - **specified appeals procedures**
- Respite scheme - **governed by need**

A **carers support scheme** has set quantitative measures for the amounts of service provided:

- Information-giving - **Number of hours of advice given**
- Training sessions - **Number provided and number of carers attending**
- Self help groups - **Number of groups and number of carers attending**
- Emotional support - **Number of hours of visiting carers in their own homes.**

This approach seemed to have been heavily influenced by the requirements of Social Services, but the respondent noted that there had lately been a willingness to move away from quantitative data collection to a more qualitative approach, to include carers' comments and letters.

A **carers helpline** uses two sets of quality indicators in assessing the service given to callers. One related to the information transmitted, the other to the listening activities involved. Each set was scaled in four levels, with the minimum interaction at the first level, graduating to a much fuller involvement at the fourth.

For example, the first level of the listening scale simply involved passing on a message while the fourth included a strong element of emotional support in crisis situations. Many of the measures were highly subjective but the respondent noted that they were effective in promoting awareness among those manning the helpline of the content of each interaction and in generating an overall appraisal of the service.

An **independent information service** offered the following standards;

- Comprehensiveness
- Impartiality
- Free, friendly, up-to-date
- Confidential
- Easily accessible
- Information provided in whatever format is required , e.g. Braille, large print, interpreter.
- Continuous feedback welcomed
- Skilled staff

A local **carers network** works within a set of quality principles guided by a set of key words. These included: **openness, carer involvement, integrity, confidentiality** and **co-ordination.**

A national organisation for carers of people with mental health problems has produced draft standards for carers support groups. Aspects covered include **accessing the service, confidentiality, publicity, rights and responsibilities, staffing and volunteers** and group **development.**

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