Carers (Recognition and Services) Act 1995: Practice Guide
1. The Social Services Inspectorate is a professional division of the Department of Health. It is headed by the Chief Inspector, who is responsible to the Secretary of State for professional advice on Government policy and on the quality of Social Services provision. The Inspectorate assists Ministers to carry out their responsibilities for personal social services, and exercises statutory powers on behalf of the Secretary of State. It is independent of the local authority, voluntary and private sector providers of social services, and seeks to include the perspectives of service users, carers and lay people in inspection work.

2. The purposes of the Social Services Inspectorate are:

- to inspect personal social services provision and its organisation and management in order to promote quality standards, improve effectiveness and efficiency, and ensure the safety and well-being of service users.

- to provide professional and social services advice and expertise to Ministers, the Department and the field on the formulation, implementation and review of social services and health policies, and the effective and efficient delivery of social services; and

- to facilitate communications between the department and the field.
DEPARTMENT OF HEALTH

SOCIAL SERVICES INSPECTORATE

CARERS (RECOGNITION AND SERVICES) ACT 1995

PRACTICE GUIDE
ACKNOWLEDGEMENTS

The Policy Guidance and Practice Guide were prepared in consultation with members of a 'Sounding Board' which consisted of carers, representatives of the National User and Carer Group, voluntary organisations, social services departments and the health service. Thanks are due to them for their contribution and to respondents from the wider consultation.

Caring Today: National Inspection of Local Authority Support for Carers is an overview based on practice in five local authorities.

What Next for Carers: Findings from an SSI Project describes fieldwork with eight local authorities known to have given priority to work with carers.

A Way Ahead for Carers: Priorities for Managers and Practitioners summarises the key issues in both reports. All the reports cover, in more detail, many aspects of this guidance. Chapters 5.6 and 7 of Caring Today and Chapter 4 of What Next for Carers discuss and give examples of good practice in assessment.

Young Carers Something to Think About summarises the discussion between academics, providers and other experts at four SSI workshops in 1995. It is a useful summary of the issues to be considered by policy makers and practitioners.
Introduction

1. The practice guidance follows the same order as the policy guidance and the Act itself. Recent SSI reports on carers and young carers address a number of issues, including assessment, in more detail than this guidance. These reports are referred to frequently; other useful material is listed at the back.

2. Most carers are adults, many are older people caring for another older person. These carers' lives will be significantly affected by caring for an ill or disabled person. Recent work has drawn attention to the situation of children and young people who take on considerable caring responsibilities within families. There are separate sections on young carers and parents of disabled children. The guidance goes into some detail about assessment of young carers as this has not been dealt with previously in guidance.

Practice aims and objectives

3. A shift in practice towards:
   - greater recognition of carers; paying attention to and taking account of what they say
   - an assessment of the "caring system" which considers the range of support available to service users and carers and encourages intervention at the right time without destroying existing informal support networks
   - an integrated family based approach which does not see either the service user or carer in isolation
   - improving practice; not increasing bureaucracy by providing the opportunity for a private conversation without an elaborate procedure. Trying to ensure that carers are not having to repeatedly provide the same information.

Scope of the Act

4. The provisions of the Act cover
   (a) Adults (people aged 18 and over) who provide or intend to provide a substantial amount of care on a regular basis
(b) Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis

(c) Parents who provide or intend to provide a substantial amount of care on a regular basis for disabled children.

5. For the purpose of the Act the term carer includes people who may or may not be a relative and who may or may not be living with the person for whom they are caring.

6. The Act describes local authorities' duties in relation to carers who provide or intend to provide a substantial amount of care on a regular basis. There has been a considerable amount of research undertaken about carers and caring.

Annex 1 provides a precis of some of this research which identifies factors associated with different types of carer and caring. Information about a carer's involvement should be gathered as part of a user's assessment. This will enable the following questions to be answered which may indicate whether somebody is providing substantial and regular care.

- What type of tasks does or will the carer undertake?
- How much time does or will the carer spend providing assistance for the user?
- How much supervision does the user require to manage her/his life?
- Is this (or will it be) a continuing commitment for the carer?

7. The nature of the caring task will vary according to the disability or illness of the user, with some conditions requiring, for example, intensive supervision or emotional support rather than physical or personal care. Some users with mental health or substance misuse problems or with conditions such as neurological disorders, dementia, cancer or HIV/AIDS will have care needs which vary over time but may present regular and substantial burdens for carers.
8. A common theme emerges from the SSI reports on carers. It was the policy in many of the authorities visited to offer carers an assessment. However, often carers did not know that they could have their needs assessed. Similarly some carers were not clear when their needs had been assessed as this was not made explicit. The process, therefore, needs to be formal insofar as it is

(a) documented

(b) mutually understood by user, carer and care manager and the results of the assessment and the care plan confirmed in writing.

A Way Ahead for Carers and Caring Today give examples of local authorities’ approaches to providing information for carers and underline the importance of a strategic, targeted approach.

Information should

- be available for carers when they need it
- be accessible to all members of the community, easy to understand and available in a variety of formats
- be part of routine assessment practice
- inform carers who appear to be eligible under the Act, of their right to request an assessment
- be available for users and carers about the local authority social services department’s complaints procedure.

The Assessment

9. **Some Key Issues**

9.1 The assessment is not a test for the carer. It should not be prescriptive but recognise carers’ knowledge and expertise. The assessment should listen to what they are saying and offer an opportunity for private discussion in which carers can candidly express their views.
9.2 In some cases it may be appropriate to offer a private discussion to both user and carer. Users and carers will need to be assured about confidentiality but it will always be important to reach agreement about how the results of such discussions will be shared with either the user or carer. Carers should be involved in the arrangements for monitoring and in all reviews. Particular aspects of the carer’s circumstances may point to the need for regular review. Carers value the co-ordination of services achieved by care management and appreciate having a named person whom they can contact.

9.3 Carers often give most of the assistance needed by the person for whom they care, and may only want a fairly small amount of help to enable them to continue caring. A PSSRU study found that some of the most cost effective care packages were where carers continued to perform caring tasks but were given sufficient support and respite to enhance their well being and maintain their own health. Equally it is important that care managers do not make assumptions about carers’ willingness to undertake the range of caring tasks, particularly those related to intimate personal care. This is highlighted in a discussion of spouse carers which emphasises the difficulties faced by some husbands or wives when their ability to cope with changed behaviour or personality and/or tasks involving physical intimacy is taken for granted.

9.4 Carers and users are not a single, homogenous group. Practitioners need to be sensitive to relationships between users and carers and to some of the stresses and difficulties, as well as benefits, of caring. Some situations will require skilful counselling and mediation, using core social work skills.

9.5 Information on charges for services and financial assessment should be clearly explained to the user and carer. A financial assessment is separate from either an assessment under Section 47 of the NHS and Community Care Act or under the Carers (Recognition and Services) Act.

9.6 When undertaking a carer’s assessment it is important to recognise the value of early intervention and on-going support in preventing deterioration in the carer’s and user’s welfare. In many instances, early access to advice and practical help can minimise the subsequent need for
increased levels of services. A swift response to requests for emergency, short-term care can alleviate carers' anxieties and avoid a possible breakdown in the caring arrangements and need for long-term care.

9.7 By including carers who are intending to provide regular or substantial care, the Act provides an opportunity to consider fully the circumstances of carers in employment who are taking on this type of caring commitment.

9.8 In assessing the carer's ability to care or continue to care, care managers should not assume a willingness on the carer to continue caring, or to continue to provide the same level of support. They will wish to bear in mind the distinction between caring about someone and caring for them. Many carers continue to care deeply about a person even though their ability to care for them may change.

10. Carers living in rural areas will be affected by the type of transport available and increased travelling times and so may have extra difficulties in gaining access to services and facilities. Care planning should take account of how best to support carers in such circumstances.
What might a carer's assessment cover?

- their perception of the situation
- the nature of their relationship with the user
- the tasks undertaken and consequent impact
- tasks carers would like help with
- their social contacts and support received from family, friends and neighbours
- their emotional, mental and physical health
- their willingness and/or ability to continue to provide care; options available to the carer, particularly carers who are in employment
- their understanding of the illness or disability of the patient, and its likely/possible development
- other responsibilities eg. work, education, family/child care commitments
- carers' strengths and ways of coping

any particular stress factors and/or aspects of the caring task which the carer finds particularly difficult.

11. Tension and conflict between user and carer

11.1 Illness and disability often create stress in family relationships and may give rise to significant tension and conflict between users and carers. Care managers may be working with complex relationships. Assessment, in such cases, is a skilful process the aim of which is to support family and other caring relationships and to assist individuals in finding their own solutions. Conflict may arise over the user's refusal of services. It can be helpful, particularly if a multi-disciplinary team is already involved, to use two workers to negotiate a resolution.

11.2 If a user refuses an assessment under Section 47 of the NHS and Community Care Act, their carer does not have the right to request an assessment under the Act as one of the triggers for a carer's assessment is that the user is being assessed.
Care managers will need to work closely with the family, user and carer to seek to resolve the situation. In such circumstances it is important that care managers see carers as individuals who may have a need for services and whom they therefore may be able to assist in their own right.

- A carer may appear to have a need for community care services and so be eligible for an assessment under Section 47(1)(a) of the NHS and Community Care Act. Local authorities should have particular regard to their function of prevention of illness under Paragraph 2 of Schedule 8 of the NHS Act 1977.

- Parents of disabled children and young carers may be eligible for services under Section 17 of the Children Act 1989.

Many such situations will be resolved through discussion and negotiation, but it is important that care managers are aware of their functions outside this Act to assist carers in these very difficult circumstances.

11.3 Tension can arise when either the user's or the carer's ability to communicate is affected by a learning, physical or mental disability. This can also be the case where either the user's or carer's first language is not English and one interprets for the other. Care managers need to communicate effectively with both users and carers so that both perspectives are known. A carer, for example, may have a long history of involvement which must be taken seriously. There are ways of overcoming communication difficulties so that all views can be sought.

11.4 Some carers find it difficult to relinquish the care of the person for whom they are caring. What Next for Carers (Chapter 4) discusses how practitioners (and other carers) might assist carers who are reluctant to accept help. A useful model for intervention is one which aims to maximise the disabled person's independence and support the carer in relinquishing some of the care. Conflict of interest is fully recognised from the viewpoint of both people.
11.5 The care plan should be a result of careful discussion with the user and carer and where differences arise, these should be recorded. Care should be taken to ensure that when requested by the user or carer, information given remains confidential and where there are conflicts of interest, interviews should be recorded separately on the file. In certain cases some thought might need to be given as to whether the carer and user should have separate records in view of possible conflicts of interest and confidential information each may give\textsuperscript{10}.

11.6 Tension and conflict can result in physical or other forms of abuse. Should this occur, \textit{No Longer Afraid: The Safeguard of Older People in Domestic Settings} (HMSO 1993) provides advice on developing policy and practice to respond to cases of older people.

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\textbf{What works in Assessment and Care Management?} \\
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\textbullet{} an integrated approach to assessment, which fully involves both user and carer and other agencies \\
\textbullet{} giving user and carer the opportunity for a separate discussion with the worker \\
\textbullet{} recognising that caring takes place within a context of existing relationships often characterised by strong feelings and mutual obligations and setting assessment sensitively in this framework \\
\textbullet{} active use of monitoring and review to pick up changing carers’ needs \\
\textbullet{} giving care managers the capacity to arrange flexible services for users and carers \\
\textbullet{} understanding that carers are most satisfied when services resulting from an assessment are carefully planned and efficiently provided. \\
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12. Equal Opportunities

12.1 All caring situations are unique and, as such, are influenced by personal and family lifestyles, relationships, religions and cultural factors. Assessments should take account of the cultural context and relationship within which caring takes place.

12.2 At the start of the assessment, ascertain whether there are any language, communication and comprehension difficulties and take steps to overcome these. There are a range of communication methods including British Sign Language, Palantype and Deaf, Blind Manual and these and others should be considered.

12.3 Local authorities should have arrangements in place so that care managers can bring in appropriate personnel which may involve the use of interpreters and/or signers when necessary. It is important that interpreters and signers receive appropriate training and understand the nature of their task. It is not appropriate to assume that users and carers should interpret or sign for each other.

12.4 SSI reports document concerns that some groups of carers were less well served than others, this included carers of very elderly people and of people with mental health problems.

12.5 Effective consultation with black and ethnic minority communities can improve assessment and services. Practical examples of some initiatives to consult with black and minority ethnic communities are described in Chapters 3 and 6 of What Next for Carers? and Chapters 6 and 8 of Caring Today.

13. Inter-Agency Working

13.1 Strategic implementation of the Act will need to involve a range of agencies besides social services. Future Community Care Plans; Children Services

Plans and Community Care Charters should therefore include reference to the agreed local response to the new legislation.
13.2 Voluntary organisations play an active role in supporting carers. Effective working between statutory and voluntary agencies can assist the implementation of this Act.

13.3 It will be important that local authorities use existing joint planning arrangements with local health agencies to ensure that effective systems are in place to implement the Act as well as to discuss their judgement of what amounts to "substantial and regular care" with local carers groups.

13.4 Some carers will now have a right to request an assessment in anticipation of a patient's discharge from hospital. This reinforces the need to involve all carers in hospital discharge planning to ensure a smooth transition from hospital to community care and to ask carers their views and include them in discussions once discharge planning has begun and in any planned admissions for elective surgery.

Young Carers

14. This section of the practice guide concentrates on assessments of young carers undertaken within the provisions of the Carers (Recognition and Services) Act. The appropriate legislative framework for the provision of services to children is Part III of the Children Act 1989. SSI, as part of its development programme on young carers, has recently published Young Carers: Something to Think About, a report of four SSI workshops held between May and July 1995. The report addresses more general questions of policy and practice concerning young carers.

15. Recognition

15.1 A young carer's right to request an assessment under the Act occurs at the time of the user's assessment. The community care assessment will, therefore, be the starting point for an assessment of a young carer.

15.2 The provision of community care services should ensure that young carers are not expected to carry inappropriate levels of caring responsibilities. It should not be assumed that children should take on similar levels of caring responsibilities as adults.
15.3 Children and young people are at an earlier and important stage of development. Denial of proper educational and social opportunities may have harmful consequences on their ability to achieve independence in adult life.

15.4 Where there are children in the family, the care manager should, by careful exploration, establish how the disabled person is assisted with his/her care needs, parenting responsibilities and whether or how the children might be helping.

15.5 If it appears to the care manager that a child or young person is providing regular and substantial care and the young carer does not request an assessment, the care manager should still consider whether there is a need to assist or relieve the child either through the provision of community care services for the user or through the provision of services to promote the welfare of the child. There may be some young carers who do not provide substantial and regular care but their development is impaired as a result of their caring responsibilities. In such situations local authorities wish to consider whether they should exercise their existing duties towards children in need.

15.6 The definition of young carer (Section 1(2)(b)) could include siblings of disabled children. Local authorities will wish to ensure that through the assessment, such carers are not expected to carry out a burdensome level of caring responsibilities which impairs their own development.

15.7 Social Services Departments should ensure that all young carers known to them have information on arrangements for community care and children's services and that they are encouraged to discuss any concerns informally with social services.
Assessment

When doing an assessment of a young carer

- listen to the child or young person and respect their views
- give time and privacy to children who may need this in order to talk about their situation
- acknowledge that this is the way the family copes with the disability or illness of a family member
- acknowledge parents’ strengths
- beware of undermining parenting capacity
- consider what is needed to assist the parent in her/his parenting role
- what needs does the child(ren) have arising from caring responsibilities?
- consider whether the caring responsibilities are restricting the child’s ability to benefit from his/her education
- consider whether the child’s emotional and social development are being impaired
- **REMEMBER** children must be allowed to be children
- provide information on the full range of relevant support services; any young carers’ groups and contact points for further advice or information on specific issues.

16. There may be differences of view between young carers and their parents which have not been expressed. Care managers will need to be alert to the possibility that children’s worlds are largely determined by their parents and that children may feel that their views have no weight. Equally they may be afraid that any admission of the difficulties may lead to a break up of the family. Such potential conflicts of views and interests may be very difficult to recognise and manage,
especially for staff who have no experience of working with children. Arrangements may have to be made to ensure that the necessary range of skills and knowledge is made available to the whole family.

17. Staff will need to be alert to the possibility that young carers and their families may have a negative and fearful view of children's services because of the Social Services Departments' child protection duties. It may have to be explained to families that children's divisions of Social Services Departments provide a wide range of services to help families.

18. Parents of disabled children

18.1 Under the provision of the Act, parents who provide substantial and regular care for disabled children will be able to request an assessment. The main legislative framework for the provision of services to families with disabled children is Part III of the Children Act 1989. Volume 6 of Regulations and Guidance is essential reading for those providing services for disabled children and their families.13

18.2 Clearly all parents, especially those with young children, provide substantial and regular care. With non-disabled children, the degree of care usually diminishes as the children grow older and become more independent. Parents of disabled children may well be providing a substantial and regular level of care beyond that which would usually be expected for a child of a similar age. Local authorities will also wish to consider the impact of a child's disability on siblings in the family.

18.3 This section is necessarily short as much of the preceding guidance which applies to carers of adults applies equally to parents of disabled children. This should be read with guidance on the Children Act 1989.
18.4 Volume 6 of Children Act 1989 Regulations and Guidance underlines the importance of

- providing early information to parents
- ascertaining the wishes and feelings of parents and children
- making an assessment of needs of the child and family leading to a plan which is regularly reviewed
- working in partnership with parents
- providing short periods of accommodation as a family support service to strengthen the ability of a family to care for their child and to promote the child's welfare
- co-ordinating services with education, health and the voluntary sector
- planning for a smooth transition to adulthood.\(^4\)

An awareness of these themes will shape any assessment requested under the Act.
ANNEX 1

CARERS (RECOGNITION AND SERVICES) ACT 1995
PRACTICE GUIDANCE

TYPES OF CARER

1. This annex provides a brief summary of research, which is described in much more detail elsewhere\(^5\). A secondary analysis of the 1985 General Household Survey undertaken by the Social Policy Research Unit at the University of York identified two different sorts of caring activity:

- those carers who are heavily involved and providing a great deal of personal and/or physical care;
- those who might be more accurately described as ‘helpers’ who provide practical help for friends, neighbours and relatives and who do not usually live in the same household.

2. It is from this analysis that a figure of 1.6 million heavily involved carers is derived. An analysis of the 1990 General Household Survey broadly confirmed these figures and indicated that those carers who were heavily involved were now even more so.

3. Parker and Lawton developed a typology of caring activities based on the eight tasks defined in the GHS survey

- Help with personal care eg. dressing, bathing, toileting.
- Physical help eg. with walking, getting in and out of bed or up and down stairs.
- Help with paperwork and financial matters.
- Other practical help eg. preparing meals, doing shopping, housework or household repairs.
- Keeping the helped person company.
- Taking the helped person out.
- Giving medicine, including injections, changing dressings.
- Keeping an eye on the helped person to see that s/he is all right.

4. The analysis also documents a wide range of involvement in caring, from people providing under two hours of help a week to those providing a hundred or more. People providing substantial hours of help, tended to undertake a greater range of tasks; personal and/or physical care were highly associated with long hours of care. Of people providing 20-49 hours a week, 58% were providing personal and/or physical care. Of those caring for 50-99 hours, the figure is 75% and for over a hundred hours it is 85%. The analysis also found that typically such carers were more likely to be sole carers, receiving little help from others, were living in the same household and were caring for someone with a mental impairment.

5. The "heavily involved carer" is likely to be someone who
- provides long hours of help;
- carries out a range of helping activities;
- is likely to provide both personal and physical assistance;
- is more likely to be looking after someone in the same household;
- is more likely to be caring for someone with a mental impairment;
- is more likely to be caring without any help from others.

6. This analysis can be criticised for potentially excluding carers of people with chronic mental health problems, eg. schizophrenia, because of its emphasis on tasks. The provision of personal care is not a major feature of caring for someone diagnosed as mentally ill. Responsibility and supervision can be a prominent feature. Other factors, for example, being the sole carer; caring for someone in the same
household are likely to be common with other carers\textsuperscript{16}. The circumstances of carers of people who misuse drugs and alcohol may be similar.

7. Carers of people with dementia often provide both personal care and supervision\textsuperscript{17}.

8. The analysis also shows that apart from those supporting people aged over 85, those caring for children (whether young or adult) and spouses in the same household are the most likely to be heavily involved and that almost the same proportion of male carers as female carers are heavily involved.
ANNEX 2

BIBLIOGRAPHY AND REFERENCES


Caring Today, Department of Health, Social Services Inspectorate 1995

What Next for Carers? Department of Health, Social Services Inspectorate 1995

Young Carers Something to Think About, Department of Health, Social Services Inspectorate 1995

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1. Information on Community Care Post April 1993
   Department of Health 1994.

2. The Right to Complain, Department of Health, Social Services Inspectorate, HMSO 1991

3. See What Next for Carers Chapter 4 page 25


5. Similarities and Differences between Informal Carers

6. For Community Care see SSI Advice Note: Discretionary Charges for Adult Services, January 1994; Charging for Residential Accommodation Guide (CRAG) and LAC (95)8 on The Standard Personal Expenses Allowances for People in Residential Accommodation.

For Children's Services see Children Act 1989 Section 17(9).

7. See also Local Authority Circular (LAC) (93)10.

Synthesises practice and research with reference to obtaining the views of older people with dementia.

**Oi, It’s my Assessment**, obtainable from People First, 207-215 Kings Cross Road, London WC1X 9DB, describes some ways of conducting assessments with people with learning disabilities. See also paragraph 12, Equal Opportunities, of this guide.


10. **LAC (89)2 Access to Personal Files Act 1987 (Social Services) Regulations.**

LAC (88)17 Personal Social Services: Confidentiality of Personal Information.

11. **Hospital Discharge Workbook**, Department of Health 1994

12. **Children Act 1989 Section 17(10)** defines "children in need" as follows:

"For purposes of this Part a child shall be taken to be in need if:-

(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part;

(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or

(c) he is disabled”.


15. Counting Care: numbers and types of informal care. Parker in Carers Research and Practice, HMSO 1992

16. Families Caring for People Diagnosed as Mentally Ill, Perring, Twigg and Atkin, HMSO 1990


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