



Carers and Disabled Children Act 2000

*Carers and  
people with parental responsibility for  
disabled children*

Practice Guidance

## Carers and Disabled Children Act 2000

### *Practice Guidance on the provisions of the Act as they affect:*

- *Carers (aged 16 or over) who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over.*
- *Persons with parental responsibility for a disabled child.*

# Contents

<b>Part I – Overview</b>	<b>Paragraph</b>
<b>Introduction</b>	
<i>Contents</i>	1
<i>Format</i>	2
<b>Context-Practice Aims and Objectives</b>	3
<b>Part II – Implementation issues (all carers)</b>	
<b>Policy background</b>	4
<i>Health</i>	6
<i>Housing</i>	7
<i>Education</i>	8
<i>Multi-agency Carers Strategy</i>	9
<i>Better Care Higher Standards</i>	11
<i>Co-ordination in relation to carers' issues</i>	14
<i>Information Strategy/Access</i>	15
<i>Referral Protocols</i>	21
<i>Multi Agency Assessment</i>	22
<i>Caring at a distance and Caring across Boundaries</i>	24
<i>Developing carers' Services</i>	28
<i>Direct Payments</i>	33
<i>Signposting to services</i>	34
<i>Carers and Employment</i>	35
<i>Equity</i>	38
<i>Monitoring Carers' experiences of the Act</i>	40
<i>Monitoring Overall</i>	41
<i>Quality Protects</i>	42
<b>Part III – Practice Guidance on Carers (Aged 16 or Over) Who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over</b>	
<b>Assessment</b>	
<i>What is the Assessment for</i>	43
<i>Right to ask for an assessment</i>	49
<i>Cared for person agrees to the assessment</i>	51
<i>Carer not wanting to be assessed</i>	52

<i>Cared for Person refuses an assessment</i>	53
<i>Who should be there?</i>	59
<i>Carers' Self Assessment</i>	61
<i>Who can assess carers?</i>	62
<i>Mainstreaming Carers assessments</i>	63
<i>Substantial and Regular</i>	65
<i>All substantial and regular carers have a right to an assessment</i>	73
<i>Children and young people affected by caring situations</i>	74
<b>Carers' Services</b>	80
<i>Carers' services that may be delivered to cared for people</i>	83
<i>Intimate services</i>	85
<i>Prescribed circumstances</i>	89
<b>Charges for services</b>	90
<b>Direct Payments</b>	93
<i>Assessment for a direct payment</i>	94
<i>Information and support services</i>	99
<i>Adult carers caring for another adult</i>	101
<b>Young Carers</b>	102
<i>Connexions</i>	104
<b>Part IV – Practice Guidance on persons with with parental responsibility for a disabled child</b>	105
<i>Employing a suitable person</i>	106
<i>Direct Payments as part of a package</i>	114
<i>Transitional arrangements for people with parental responsibility for disabled children</i>	115
<i>Deciding how direct payments are to be used, calculating the amount of the direct payment and making the payment</i>	117

# Part I Overview

## Introduction

### Contents

- 1 This practice guidance sets out how local councils with social services responsibilities (local councils) should implement the policy set out in the Policy Guidance on the Carers and Disabled Children Act 2000. It follows the same order as the policy guidance. It is in three parts:
  - Implementation issues councils should address in relation to all carers
  - Guidance on how to implement the Act as it affects carers (aged 16 or over) who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over
  - Guidance on how to implement the Act as it affects people with parental responsibility for a disabled child who provide or intend to provide a substantial amount of care on a regular basis for a disabled child or children.

### Format

- 2 To illustrate the potential for flexibility, creativity, cost-effectiveness and innovation inherent in local council's new powers, the guide contains a number of case studies that give examples of how the Act could work. There is also a *Practitioner's Guide to Carers' Assessments*, which is designed to pull together into one document key good practice messages on carers' assessments under the Act. The Practitioner's Guide is primarily aimed at staff carrying out carers' assessments of adults caring for adults. Where children are affected by illness or disability in the family, the appropriate guidance will be *the Framework for the Assessment of Children in Need and their Families* (Department of Health et al 2000) which deals with young carers and disabled children and their families in some detail. Care managers (adults) who identify that community care service-users have parenting responsibilities, will need to undertake an initial child in

need assessment and/or involve staff from children's services to make sure the children's developmental needs are identified and addressed appropriately.

## Context – Practice Aims and Objectives

3 The Government's aim is actively to support carers. In implementing the Act, authorities will wish to ensure there is a shift in practice towards:

- Improvements in the identification of carers whose care is being taken into account when services to cared for people are being considered
- Improvements in the process of assessing the impact of the caring role on the carer and thus whether the care provided is regular and substantial
- Effective use of the Framework for the Assessment of Children in Need and their Families, in particular to acknowledge and support people with parental responsibility in their parenting role whilst maintaining the focus on the welfare of the child
- Greater recognition of carers, and in particular listening to them about the outcomes they would like to see following an assessment
- Innovation in relation to meeting the assessed needs of carers who are eligible for services under the provisions of the Act (including where needs may not be obvious or immediate, so as to prevent breakdown of the caring situation)
- Assessments that are pragmatic and as complete as they need to be – avoiding unnecessary bureaucracy but focusing on what the carer sees as the outcome required
- A holistic/integrated family based approach to assessment that sees carers and cared for people as partners in the caring relationship and acknowledges the abilities and contributions of all as well as their needs.



## Part II Implementation Issues (all carers)

- 4 The Policy Guidance sets out the national policy context for implementation of the Act. As the report of the National Carers' Strategy, *Caring About Carers* makes clear (Chapter 6.1), the Government's aim is to enable carers to make more choices for themselves and to have more control over their lives – for their own health and well-being.
- 5 While local councils with social services responsibilities have the lead responsibility for implementation of the Act, all services, not just local authority services, need to recognise carers as individuals in their own right and be aware that early identification can help to support the sustainability of the caring role. Effective policies relating to carers in all relevant agencies, combined with effective communication between agencies, are therefore crucial to supporting carers. In particular Health, Housing and Education have key roles:

### *Health*

- 6 General Practitioners and other primary care staff will often be the first point of contact for carers. Many more carers receive services from them than from Social Services. A caring role will also often begin at the point that the cared for person is discharged from hospital. Health staff have a key role in helping carers access the support they need.

### Checklist for GPs and Primary Care Teams to help carers (Caring About Carers, p55)

- Have you identified those of your patients who are carers, and patients who have a carer?
- Do you check carers' physical and emotional health whenever a suitable opportunity arises and at least once a year
- Do you routinely tell carers that they can ask social services for an assessment of their own needs?
- Do you *always* ask patients who have carers whether they are happy for health information about them to be told to their carer?
- Do you know whether there is a carers' support group or carers' centre in your area, and do you tell carers about them?

### *Housing*

- 7 Housing that is warm, safe, secure and manageable is an important ingredient to enhancing the quality of life of those being cared for. Councils with social services responsibilities need to ensure that people have the right housing to help meet their care and support needs. This can make a real difference to carers. In planning services for carers, councils with social services responsibilities need to involve housing authorities and other housing professionals to ensure that the housing needs of cared for people have been properly addressed.

### *Education*

- 8 Effective joint working with Education will be essential to ensure that young carers can be identified and supported appropriately by schools (see Circular 10/99 School Inclusion: Pupil Support, paragraphs 3.10 to 3.12). The stresses on parent carers of disabled children will be reduced when disabled children's social health and educational needs are met in an integrated and responsive way.

### *Multi-agency Carers' Strategy*

- 9 As part of the implementation of the Act, therefore, local councils will wish to build on or develop a multi-agency carers' support strategy following the key themes in 'Caring About Carers'. They

will need to do this in partnership with key agencies which will include:

- Health Authorities
- NHS Trusts
- Primary Care Groups and Primary Care Trusts
- Care Trusts
- Mental Health and Social Care Trusts
- Housing Authorities
- Voluntary Organisations and Carers' Groups
- The Department of Social Security, via District Offices
- Employment Services
- Skills and Training Councils
- Local Education Authorities
- The developing Connexions service
- Disabled People's Organisations
- Centres for Independent Living
- Direct Payments Support Services
- Organisations of Disabled Parents
- Young Carers' projects

10 In addition to Caring About Carers, two Government documents will be particularly helpful to local councils in co-ordinating a multi-agency strategy:

- The Government published in 2000, Quality Standards for Local Carers Support Services (adults). This document sets standards that should apply to all services that affect carers of adults

- The Government leaflet, *How To Get Help In Looking After Someone, A Carers' Guide To A Carer's Assessment*, telling carers how to access a carers' assessment is being distributed to local councils and other agencies (and is included in the guidance pack)

### *Better Care Higher Standards*

- 11 Local Better Care Higher Standards charters will also be key in underpinning such a strategy. Such charters tell anyone who needs care and support over the longer term and their carers what standards to expect from local housing, health and social services in the provision of services and what to do if things go wrong. Charters are produced annually in consultation with service users and carers and are aimed at driving up local standards across six important areas of service provision including caring for carers.
- 12 Charters form part of the Government's drive to make public services more accessible, improving them by joined up working and putting services on a Best Value basis. Councils with social services responsibilities need to ensure that carers are provided with a copy of their local charter and are encouraged to provide feedback on their experience of service provision. Carers need to be consulted and involved in the development of new charter standards and targets as they affect carers and those being cared for.
- 13 Monitoring of the charter at a local level will be focused on users' and carers' experiences and views of services. The Government expects authorities to ensure that users and carers are advised of how to feed back their views and become involved in enhancing local charter standards across social services, housing and health provision.

### *Co-ordination in relation to carers' issues*

- 14 Co-ordination between agencies should already be developing through
  - Community Care Plans
  - Children's Services Plans
  - Early Years Development and Childcare Plans
  - Carers' Special Grant Plans

- Quality Protects Management Action Plans
- Joint Investment Plans Health Improvement Plans
- Better Care, Higher Standards Charters
- Implementation of National Service Frameworks

### *Information Strategy/Access*

15 Local councils need to have in place strategies to ensure public awareness of the services that are available to disabled people and their families. Any strategy will need to be linked to **Information for social care** *A framework for improving quality in social care through better use of information and information technology* which addressed the following areas:

- Citizen/service user focus
- Accessibility and inclusiveness
- Accountability
- Sharing of information
- Culture

These areas are based on the key themes of the social care quality strategy (*A Quality Strategy for Social Care* DH August 2000) and the key principles of the e-government strategy (*e-government: a strategic framework for public services in the information age* Cabinet Office April 2000).

- 16 The Children Act 1989 (Schedule 2, paragraph 1) requires local councils to provide information about services available in their area and to take reasonable steps to disseminate this information to those people who might benefit from using services.
- 17 Providing information about existing services will be particularly important when discussing the option of Direct Payments.
- 18 The Mental Health Information Strategy requires local councils to begin to address a new set of information issues including agreeing common definitions, sharing data and addressing quality of care.

- 19 Under the Disability Discrimination Act local councils have to take reasonable steps to change practices, policies or procedures that make it impossible or unreasonably difficult for disabled people to use a service. This applies also to the provision of information.
- 20 Local councils will also need to ensure that key agencies have appropriate information readily accessible relating to the new rights of carers, especially their right to request an assessment under the Act. Reports from SSI give clear messages about the need for information strategies to be effective within and across agencies. As part of the Quality Protects Programme, local councils are required to provide families with disabled children with information about services on a multi-agency basis. This information should refer to direct payments. The importance of publicity designed to reach carers is underlined by research findings that show that at the moment it is nearly always professionals who offer assessments rather than carers requesting them.<sup>1</sup> Particular efforts will need to be made to ensure take-up by harder to reach groups of carers, for example carers from ethnic minorities. It would be helpful if information provided to parents about Special Educational Needs processes and local services were updated to refer to direct payments to ensure parents of disabled children were aware of the flexibility they may offer.

### *Referral Protocols*

- 21 Local councils should ensure that all relevant agencies understand the ways that carers can access carers' assessments. The Framework for Assessment of Children in Need and their Families emphasises the importance of a shared understanding between agencies of how to refer a possible child in need to social services departments. Protocols should similarly be developed in relation to adult carers of adults to make referrals for carers' assessments easier. This might particularly help carers where a cared for adult refuses to be assessed. Simple documentation should be designed and agreed for use between parties to the protocol. Such a form would record that in the opinion of a professional, GP, voluntary sector worker, carers' group representative etc that the carer being referred was a substantial and regular carer within the terms of the Act and local eligibility criteria. The virtue of such a form would be that it could corroborate the impact of the caring responsibility on the carer, without breaching any duty of confidentiality to the cared for person. The exercise of judgement about whether the carer does in fact have a regular and substantial caring responsibility must remain with local councils.

---

<sup>1</sup> Carers Needs and the Carers Act, Social Policy Research Unit, June 2000 p.v

### Sample Referral Form

I [name], [profession/role/carers' group] can confirm that [carer's name] of [carer's address] appears to me to be a substantial and regular carer [for ....name of cared for person – name to be omitted where cared for person is refusing to be assessed and does not consent to name being given] within the terms of the Carers and Disabled Children Act 2000 and the eligibility criteria of [authority name] (these could be set out in bullet point format on the referral form) and that s/he is requesting a carer's assessment.

Signed [ ] Contact details:

### Multi-agency assessment

- 22 Agreements may be drawn up to allow, where appropriate, staff other than local council staff to assess carers (see below 'Who can assess carers?' paragraph 62). The National Service Framework for Older People sets out the single assessment process for older people and their carers. Standard 6 of the Mental Health National Service Framework, sets out the process for carers of people with mental illness subject to the Care Programme Approach.
- 23 Where assessments include disabled children or young carers statutory guidance is provided in the *Framework for the Assessment of Children in Need and their Families*.

### Caring at a Distance and Caring across Boundaries

- 24 Particular difficulties may be faced by carers who care for people who live a long way away from them and/or who live across local council boundaries. The cared for person will then be a user or potential user of services from a different local council. Problems may be aggravated where they care for more than one person.
- 25 The carer's assessment will be particularly crucial in these situations, since a carer's role may not appear substantial and regular if the assessment does not take into account the inconvenience of caring at a distance, or if one carer's assessment relating to one cared for person in one authority is carried out in isolation without regard for the impact of the carer's other responsibilities.

- 26 Local councils will need to work in partnership with neighbouring and other local councils – many carers commute long distances to provide care at weekends, for example – to ensure that carers’ needs are appropriately assessed and appropriate support is provided. The basic principle behind such joint work should be as follows:
- Where the carer cares long distance for only one cared for person and that person is eligible for support, the community care service-user’s home authority has responsibility for the carer’s assessment and provision of services even if carers’ services (such as buying a washing machine) might need to be provided in a different local council area. Where the carer cares for more than one person in more than one local council area, but only one cared for person is eligible for community care services, the home local council of the eligible cared for person has responsibility for the carer’s assessment and for leading on any co-ordination that may be required between authorities
  - Where two cared for people in two different authorities are eligible for community care services, those authorities should agree how a carer’s assessment may best be conducted ensuring between them that all relevant information is available and negotiating how carer’s services may need to be provided **to ensure the sustainability of the multiple caring roles if this outcome is in the best interests of the carer.**
- 27 One way for neighbouring local councils to plan to support such carers effectively, rather than simply responding in an ad hoc way, would be for them to agree and publish protocols around carers’ assessments in such situations.

### *Developing Carers’ Services*

- 28 While the vast majority of support to carers will continue to be in the form of community care and Children Act services rather than carers’ services, implementation of the Act will require innovation at both a strategic and practitioner level. At a strategic level commissioning managers will need to identify in consultation with carers and carers’ organisations the sorts of local services that currently exist or should be developed to support carers of adults or children (see below Carers’ Services paragraph 80). Such services might be either provided in-house or be commissioned in the voluntary or private sector.

- 29 At practitioner level, care managers, and other assessors, will need to show initiative in purchasing services for carers, and a willingness to provide direct payments so that carers can manage their own services themselves if that is what they want to do.
- 30 Each local authority should aim to produce and publish an *A to Z of local carer services* and other sources of support, like local carer drop-in-centres.
- 31 Both commissioners and practitioners will need to listen carefully to what carers see as the sorts of services able to deliver outcomes most likely to help them. Local councils will find that over time the following mechanisms may be particularly helpful in assisting staff to develop appropriate carers' services:
- Training for staff using the e-learning material on the Act at [www.carers.gov.uk/elearningwelcome.htm](http://www.carers.gov.uk/elearningwelcome.htm)
  - Joint training with staff from other agencies, and especially training where carers are involved as trainers
  - Training for adults' and children's staff together, focussing on:
    - the transition from children's to adults' services
    - the importance of holistic assessments of family needs
    - the impact on disability on family life
    - how to ensure that relevant expertise is shared in individual situations, such as how best to assess young carers
  - Addressing carers' services and assessments in multi-agency strategies and across adults' and children's services
  - Addressing carers' services and assessments in staff supervision
  - Quality audit of carers' assessments (carers' plans, statements of carers' needs, carers' plans) and referral processes
  - Carer surveys (see below paragraph 40)

- 32 As part of implementing the Act local councils will want to ensure that carers are fully informed of the current availability of free community-based services in the voluntary sector.

### *Direct Payments*

- 33 Local councils should already have in place systems and support services to enable direct payments to be made under the Community Care (Direct Payments) Act 1996. Local councils should build on the expertise that they and nearby authorities have already developed and adapt, develop or replicate these schemes for carers, as appropriate, and according to the wishes and views of local carers and disabled people. Joint work should be encouraged between carers' groups, young carers' projects, direct payments support services, organisations for disabled parents and parents of disabled children.

### *Signposting to services*

- 34 Local councils should ensure that care managers have the sign-posting information to help them find services that can support carers. Research shows care managers are not always aware of the network of services that can help carers<sup>2</sup> (either substantial and regular carers or those with lesser needs). Care managers cannot be expected to know in detail about all the services that might help carers in their caring role or to maintain their health and well-being. They should, however, know how to access information and be aware of the range of key agencies to use as a starting point to help carers get what they need.

---

<sup>2</sup> Carers Needs and the Carers Act, Social Policy Research Unit, June 2000 p.v

### Example 1: Helping carers access the information they need

*Tina cares for John who has multiple sclerosis. She is prepared to continue to do the majority of the personal care, but is very keen to be supported in accessing skills to help her to return to work full-time when her children leave home in the next couple of years.*

*A carer's assessment is carried out. The care manager is not an expert on children's services and so involves a professional from the children's team. The care manager also knows very little about how best Tina can be helped to retrain. However, the care manager knows how to put Tina in touch with the Training and Skills Council and has arranged a weekly break for her to attend a computer skills course. The care manager has also arranged for the local welfare rights service to advise Tina on what would happen if she took on a part-time job and then had to give it up again because of the pressures of the caring role.*

## Carers and employment

35 Carers should be supported to stay in work, or to return to work, where this is what they want to do. The local council should therefore:

- identify links with partner agencies to ensure carers assessed have access to good quality information on training and other support to build confidence prior to returning to work
- make sure that the Welfare to Work Joint Investment Plan cross-refers to the multi-agency carers' strategy and state where the local council's policy on carers and employment is addressed
- audit services to identify how well they support carers through providing flexible and reliable packages of care which allow carers to continue to work
- remember that if involvement in employment is or will be at risk this constitutes a critical risk to the sustainability of the caring role (see below especially paragraphs 68 and 69).

- 36 People with parental responsibility for disabled children will also benefit from joining or re-joining the workforce. Such carers often face difficulties re-entering the workforce because of lack of suitable child-care services. Many parents of disabled children would like to return to work and, if they were able to do so, would benefit socially and emotionally as well as financially.

### Example 2: Supporting parents of disabled children to work

*Rosie is 8 and has a severe learning disability. She attends a special school and has on occasion successfully attended a mainstream after-school club. Her care plan specifies three breaks a week of four hours each, currently provided by a home carer. Rosie's lone mother, Kathy, is a qualified nurse who would like to return to work full-time. Kathy has only been able to work on an agency basis because of the difficulties in arranging child-care for Rosie.*

*The family's needs have been assessed as set out in the Assessment Framework Guidance and the assessment included consideration of Kathy's needs as well as Rosie's. She is now using direct payments to provide childcare in a way which better fits with her aspirations and chosen lifestyle. She funds some of the cost of the after-school club through her childcare tax credit (part of Working Families Tax Credit) and the remainder through direct payments. This enables Rosie to attend the after-school club 5 evenings a week, which promotes her inclusion in mainstream activities. This is also a more cost-effective approach for the local council than the homecare option.*

*Kathy can now work as a full time community nurse. This arrangement meets the social and financial needs of the mother and also promotes Rosie's welfare.*

- 37 The local council and **all partner agencies** who provide services should investigate:
- how well appointments and multi-agency assessments, including at discharge from hospital, are arranged to accommodate the fact that the carer is working (in terms of both timing of assessments and expectations of how much caring responsibility a working carer can take on)

- how carers they employ could be offered the facilities to provide each other with support either through group meetings, use of email facilities etc
- how good their own employment policies and practices are in terms of work-life balance, flexible working practices, support to staff through occupational health etc
- how the experiences of carers they employ can be harnessed through group consultancy to make sure flexible employment policies work in practice
- how well these policies are promoted to carers who are employees

## *Equity*

- 38 Local councils will need to make sure that their eligibility criteria for carers' assessments are clear and published. Referrals for children's services should be considered within the guidance set out in the Assessment Framework. By focusing on outcomes for carers it is likely that there will be situations where a particular family, as a result of a carer's assessment, receives a service that other families, in similar circumstances, might not be able to get (laundry, gardening, taxi fares etc). This might be because the judgement was made that in one situation the desirability of achieving a certain outcome was important to the sustainability of the caring role while in another it was not. Transparency about how decisions are made in relation to carers will be essential.
- 39 The need for outcomes to be stated and agreed with users and carers means that eligibility criteria and assessments must acknowledge the role of cultural and religious identification in individuals' lives. Without some shared understanding it will be difficult for carers and assessors to agree appropriate support or a carer's plan. Councils must ensure that their staff are culturally competent or can access relevant expertise so as not to disadvantage carers from black and ethnic minority communities.<sup>3</sup>

---

<sup>3</sup> The Good Practice Guide: Supporting Black Carers, put together by the National Black Carers Workers' Network will be available from Summer 2001

### *Monitoring Carers' experiences of the Act*

- 40 Local councils will want to develop mechanisms, for example small-scale surveys of carers who have been assessed, to identify carer's experience of and satisfaction with the assessment process and outcomes. Local councils will also want to make sure that partner agencies such as Primary Care Groups and voluntary organisations, carers' groups and individual carers can feedback on how the act is working locally. Complaints from carers will need to be collated, and feedback on Better Care Higher Standards charter. Best value reviews will require that individual carers are consulted about their satisfaction with assessment and service provision. Care should be taken to ensure that all groups of carers are included.

### *Monitoring Implementation overall*

- 41 Primary responsibility for monitoring implementation lies with local councils through their performance management arrangements. The Department of Health will also monitor progress through the performance assessment system. This will be mainly carried out by Social Services Inspectorate Social Care Regions' monitoring, through the bi-annual Position Statements and the evaluation of relevant plans. Data from the relevant DH statistical returns, particularly in relation to carers' assessments, will be used to inform and support monitoring. Evaluation of services to carers will also feature in certain SSI inspections.

### *Quality Protects*

- 42 From April 2001 services for disabled children are a priority for spending under the increased Children's Special Grant. One of the Government's objectives for children's social services is to increase the amount of family support services available to families with disabled children. Direct payments will be one means of achieving this objective. Local councils have to report annually through their Quality Protects Management Action Plans on progress in achieving all objectives in relation to disabled children.

# Part III

## Practice Guidance on carers (aged 16 or over) who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over.

### The Assessment

*A Practitioner's Guide to a Carer's Assessment* (adults) is provided within the family of guidance documents on the Act.

#### *What is the assessment for?*

- 43 A carers' assessment under the Carers and Disabled Children Act 2000 is carried out at the request of the carer in order:
- to determine whether the carer is eligible for support
  - to determine the support needs of the carer (ie what will help the carer in their caring role and help them to maintain their own health and well-being).
  - to see if those needs can be met by social or other services
- 44 It is also the point at which a carer may wish to raise, or may need to be encouraged to think about, whether their caring role is a sustainable one. This may well be a point at which a carer begins to express doubts about their ability or willingness to continue to care. Particularly sensitive support may need to be given in certain circumstances to enable carers to identify that while they may continue to care **about** the person, the choice to provide care **for** the person may no longer be in the best interest of either the carer or the person they care for. It must also be remembered that there may be situations where the cared for person has never wished, or no longer wishes, to be cared for by a family member but thought there was no choice. A holistic assessment in this situation will need to address alternative solutions such as independent living for the cared for person, while acknowledging the contribution the carer has made and helping them to let go.
- 45 The carer's assessment should be a carer-centred process, listening to the carer, valuing their experience, focusing on outcomes (not just services) that the carer thinks are important in terms of supporting

them in their caring role or maintaining their health and well being. It should be a pragmatic process focused on identifying the best possible outcome for the carer within the context of a holistic assessment of the caring situation.

- 46 The best possible outcome will depend on the nature of the impact of the caring situation on the carer. An assessment must therefore value the carer's views and start from what the carer thinks are the most important issues. While there may be other issues underlying those that the carer presents with, it may take time to identify these. Carers' assessments, like all assessments, can sometimes most appropriately be simple one-off events, but are often more complex ongoing processes. At all points, practitioners should recognise carers' knowledge and expertise. Any solutions and service options should be negotiated with the carer rather than imposed.
- 47 Conducting a carer's assessment is not always easy for a variety of reasons. Research shows that many carers do not want to discuss commitments outside the caring relationship as part of their assessment and some do not even want to be asked whether they are willing to carry on caring. However, simple pragmatic responses to carers' presenting needs make it more likely that the carer will open up on more complex and personal issues at a later stage, where this is necessary. A carer's assessment is not a process for its own sake. It should be as simple or as complex as it needs to be to deliver an outcome that makes it easier for the carer to care.
- 48 Outcomes for the carer can be delivered in a number of ways:
- Advice, information, social work as part of the care management process
  - A modification of the package for the cared for person that provides the carer with additional breaks etc through the delivery of additional community care services to the cared for person
  - The provision of 'Carers' Services' through the Act
  - Sign-posting to community services that the carer can access directly and free of charge (such as carers' centres, carers' support groups etc)

### *Right to ask for an assessment*

- 49 Under the Act, carers have a right to ask for an assessment. In practice, authorities may wish to have a policy of offering carers an initial assessment in circumstances where the carer is providing support to a community care service-user. This would be particularly important where that carer's contribution to the overall care needs of the cared for person had been taken into account when assessing the need for community care services for the cared for person.
- 50 At the very least, local councils will want to:
- Work with a range of agencies and carers' organisations to publicise carers' rights through leaflets, roadshows, local radio etc
  - ensure that a copy of the Government leaflet *Help in Looking After Someone: A Carer's Guide To A Carer's Assessment* is routinely handed or sent to carers when they are identified as part of a community care service-user's assessment (a copy of this leaflet is enclosed with the guidance pack)
  - ensure that where necessary the above are provided in languages and formats appropriate for their local communities, or that there is access to translators and interpreters

### *Cared for person agrees to assessment*

- 51 In the straightforward situation where a cared for person is agreeing to an assessment and is eligible for support, information about a carer's involvement may be gathered as part of that assessment (but see also **Who should be there?** Below paragraph 59). If the impact of the caring role on the carer(s) is such that their input is not deemed to be equivalent to a substantial amount of care on a regular basis, the carer(s) should still be involved in the cared for person's assessment if this is what the cared for person wants.

### *Carer not wanting to be assessed*

- 52 If a carer does not wish to be described as a carer or to be assessed, there may be a need for sensitive discussion of why this may be. It will be important for carers to understand that the assessment can trigger services not otherwise available to the carer. A carer should not be recorded as a carer unless they wish to be so. If the carer does

not want an assessment, the package to the cared for person should still reflect the carer's need for a break and accordingly may include additional services delivered to the cared for person to enable the carer to take a break. As a matter of course, the carer should be given information about community services such as carer's centres, carer support groups, support groups that help families affected by specific conditions etc.

### *Cared for person refuses an assessment*

- 53 Where the cared for person refuses an assessment, it may be clear to the local council that the cared for person is nonetheless eligible for community care services. It may be that the cared for person has previously consented to an assessment and in the past the carer had an assessment under the Carers (Recognition and Services) Act 1995. If so, the local council should take into account any relevant information revealed through such a previous carer's assessment.
- 54 Where the eligibility of the cared for person is established, despite their refusal of an assessment, and the carer has requested an assessment under the Act, an initial carer's assessment can establish the degree of impact of the caring responsibility on the carer, and whether a full carer's assessment is required.
- 55 There will be situations where it will be more difficult to establish whether the cared for person would meet the local criteria for support under community care legislation. In the absence of referral protocols outlined above, the council will still want to have some corroboration of what the carer is telling them from such sources. Sometimes the duty of confidentiality to the cared for person may make this complicated. Councils will, however, wish to ensure those with relevant information understand the local criteria for community care services and are given the opportunity of signing a declaration form similar to that used by those with whom the authority has an agreement. This could be helpful where, for example, the cared for person is registered with a GP located just outside of the area covered by any local protocols or agreements.
- 56 If there is no other source of supporting evidence of the carer's situation, local councils may decide, where it appears appropriate, to conduct an initial carer's assessment. The fact that the cared for person refuses an assessment, or any support other than that provided by the carer, may in certain circumstances actually underline the fact that the carer's contribution is indeed substantial and regular.

Assessing the carer may provide the opportunity for the local council at least to meet the cared for person. Even in the absence of supporting information a local council may decide that, in exceptional circumstances, they will use their discretion to support the carer anyway.

- 57 Where the carer wants an assessment but says that the cared for person will refuse an assessment, the carer may ask the council not to contact the cared for person. Sensitivity needs to be exercised in these situations. Best practice would be to be open with the cared for person about the source of any referral. Therefore it would be appropriate to consult with the carer as to why it is not possible to discuss the referral with the cared for person, and explain that a sensitive approach can be made.
- 58 If the carer is adamant that there must be no reference to their referral, then this effectively prevents the council from approaching the cared for person, unless otherwise there is reason to believe there is a risk of real harm to the carer or the cared for person. It should be explained to the carer that at this point they are effectively denying themselves support under the Act.

### *Who should be there?*

- 59 Carers' assessments can be carried out as part of a holistic assessment with user and carer together. Or the carer may want some confidential time with the assessor to talk about the impact of their caring role. Likewise the cared for person should always be offered some confidential time away from the carer as part of the assessment. It will often be best to arrange such confidential time for the carer over the phone, and away from the home or while the cared for person is out, so as not to increase any possible tension over 'being talked about behind my back'.

### *Support in the assessment*

- 60 Carers should be told of their right to have a friend or advocate present if they would wish to do so. The long term care charter, *Better Care, Higher Standards* expects local charters to give details of how people can get in touch with organisations in their local area who can provide independent advice or advocacy services. This may be particularly important where there are particular religious or cultural factors that impact on the caring situation. In addition, there may be language, communication or comprehension difficulties

requiring signers, interpreters or others to be present. There are different forms of advocacy, but the role of the advocate is to work for the individual, supporting them in expressing choices, facilitating the communication of this to other parties, and working with the individual so that their choices are respected and acted upon.

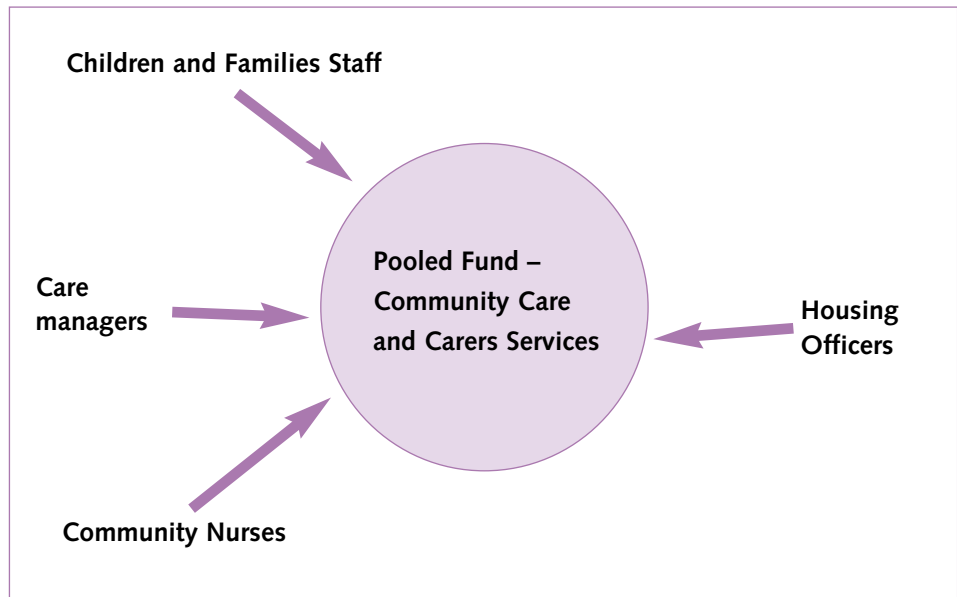
### *Carers' Self Assessment*

- 61 Asking carers to complete a self-assessment form can help them prepare for assessment so they can get the best out of it. However, best practice suggests that leaving carers to fill in such forms on their own cannot replace face-to-face assessment with a sensitive well-informed professional.

### *Who can assess carers?*

- 62 Local councils have the duty to carry out carers' assessments if requested under the Act. However, as part of their caring role, carers often come into contact with professional staff from a range of different agencies. There are situations where health, or housing agency staff may be better placed to carry out carers' assessments on behalf of the local council. In order to allow this flexibility local councils will need to ensure appropriate arrangements are put in place. This can be done in the following ways:
- Under s113 of the Local Government Act 1972, a local council can have Health Authority staff put at its disposal for the discharge of the local council's functions. Agreements between the local council and the relevant health agencies will need to be put in place before any such 'secondment' can take place.
  - A pooled budget with appropriate aims and objectives and for which the health-related functions are specified, could be set up in such a way that it could be used as the mechanism for staff other than local council staff assessing carers and providing carers' services to the carer or additional services to the cared for person (see Fig 1).

**Figure 1. Multi-agency access to pooled funds**



Such arrangements may be beneficial in a number of situations.

### Example 3: Individual response through 'secondment' to deliver carer's assessment

*Grace cares for her husband Desmond who has diabetes and is disabled. They were both born in Jamaica. A District Nurse, Jasmine, from the same background visits three times a week to change dressings and already knows Grace and Desmond well. Grace finds her caring role is beginning to affect her own health. Jasmine notifies the local council of the changing circumstances within the caring relationship. At this point Grace asks if Jasmine can carry out the carers' assessment.*

*There are certain tensions in the relationship between Grace and Desmond. Because Jasmine has the right skills and an understanding of patois and particular cultural issues, the local council agrees that Jasmine would be the best person to conduct the assessment, subject to Desmond's care manager agreeing any resulting changes to the care package. This is possible because the local council already has an agreement in place with the Community NHS Trust for which the District Nurse works.*

## *Mainstreaming Carers' Assessments*

- 63 Nevertheless, it will not normally be good practice for a local council to delegate responsibility for carers' assessments **wholesale**. This is because of the need for effective holistic assessments to include both carers and cared for people's experiences in one process. It is not possible for a local authority to delegate its assessment responsibilities to a voluntary organisation. If a voluntary organisation is aware of a carer who is likely to be in difficulty in sustaining their caring role, it may alert the local council to the need for a carer's assessment, and may provide the local authority with relevant information. However, it must be the local council which carries out the assessment.
- 64 The flexibility for voluntary organisations to provide services funded out of Carers' Special Grant direct to cared for people to support carers on the basis of the voluntary organisations' own evaluation of the situation is not a delegation of the local council's statutory function of assessment, and the voluntary organisation is not then providing "community care services". This grant flexibility is aimed at helping local councils reach out to those carers (and the people they care for) who for a variety of cultural and psychological and other reasons are reluctant to approach social services for help.

## *Substantial and Regular*

- 65 Under the provisions of the Act, carers aged 16 or over are eligible for an assessment of their ability to provide care and continue to provide care:
- Where the local council is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services
  - Where they provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over.
- 66 Accordingly, as part of a holistic assessment of a person who is eligible for community care support, practitioners should take care to identify all carers who currently provide help, and determine which of those carers are caring on a regular and substantial basis.

- 67 It is not only the time spent each week caring that has an impact on carers. For some, such as those caring for adults with learning disabilities, the caring role can have the additional impact of being a life long commitment. For others, such as those caring for adults with severe mental health problems, caring can be a sporadic or cyclical responsibility. The carer may not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or actively seeking to prevent, the next crisis. In addition, caring responsibilities may conflict with other family responsibilities, such as parenting or holding down a job. Any assessment of the carer's need for support has to look at the impact of the whole caring situation.
- 68 The term 'substantial and regular' is not defined in this guidance. In any given situation, the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions
- Is the caring role sustainable?
  - How great is the risk of the caring role becoming unsustainable?
- 69 The key factors to consider in identifying sustainability of the caring role are:
- **Autonomy.** This describes 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. It is dependent on recognition of their role and an agreed sense of shared responsibility between the local councils and the carer/s
  - **Health and Safety.** Here the issues of risk to the carer's own health of maintaining their caring role at its current level must be looked at in view of their own age and other commitments. For example, cover may need to be provided in such a way as to allow the carer to attend medical and dental appointments as and when they need. Suitable equipment may need to be installed to aid the carer in providing intimate support to the person they care for. Issues may need to be discussed around the safety of the carer from harm caused by the person cared for. Harm can be caused intentionally or unintentionally.

- Managing daily routines. Can carers look after their own domestic needs and other daily routines while sustaining their chosen caring role? As for community care service users, this area may have physical, cognitive and mental aspects
- Involvement. To what extent do carers have freedom to maintain relationships, employment, interests and other commitments alongside their caring responsibilities.

70 The extent of risk to the sustainability of the caring role 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. These risks are graded from critical, substantial, moderate to low.

Combining the key factors of sustainability to the caring role and the extent of risk should form the basis of the eligibility framework that local authorities should implement. Councils should consider the level at which they fix eligibility in relation to sustainability of the caring role in the light of the following bands of risk:

- 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.

- 71 There should be no assumptions made about the causes of risk. Some carers may be at risk because of their age, health status or own disabilities. There are carers who are at risk and suffering stress related illnesses because of the condition of the person they care for. Many carers are at risk because they have become socially isolated due to lack of support for them in their caring role and this has led to the breakdown of key relationships and networks. Although these important factors are not built into the eligibility criteria, they will form part of the information to be gathered as a matter of professional practice in identifying the impact on the carer of the caring role. (See *Practitioner's Guide to Carers' Assessments* throughout)

#### Example 4: What is the impact of the caring role?

*Mr Appleby is 86. He has severe arthritis. He needs help to get up in the morning, to wash, to get into his wheelchair, to use the toilet, to undress and to go to bed. Mrs Appleby is 84. She is helped by her daughter Teresa, who is 44 and lives nearby.*

*Mr Appleby is eligible for community care services. There are potentially two substantial and regular carers here. Teresa is willing, with appropriate instruction/ equipment available etc, to help Mr Appleby into his wheelchair etc without undue risk to her health. Mrs Appleby is not able to carry out this task, but, if Teresa carries out the physically demanding tasks, Mrs Appleby is quite happy to carry out all the other associated intimate care tasks. Mrs Appleby sees herself primarily as a wife and is quite content with her caring role since her husband would have done the same for her if the situation were reversed. Teresa, on the other hand, is also trying to hold down a job, making it impossible for her to contribute at key times when Mrs Appleby needs her help. She is also bringing up children and without help in her caring role she will not be able to give them the support they need from her as a mother.*

- 72 It is in the light of such factors that the substantial and regular test should be applied. The risk of Teresa losing her job is particularly significant. Once out of the labour market it may be very difficult for her to return to it.

### *All substantial and regular carers have a right to an assessment*

- 73 It is important that **all** substantial and regular carers have access to an assessment and that there is no assumption that a 'main' or 'primary' carer is the only substantial and regular carer. Where there are children in the family, there are important additional issues that may need to be addressed in the initial assessment.

### *Children and young people affected by caring situations*

- 74 An initial assessment of adult carers and service-users **must** always clarify whether they have a parenting role. Sometimes children of the family may be children in need as a result of the impact of disability or illness on a family member. If so children's services staff should be involved and an assessment undertaken following the guidance *the Framework for Assessing Children in Need and their Families*. (See in particular paragraphs 3.61 – 3.63)

### *When choosing to care is in the best interests of the 16 or 17 year old*

- 75 'Young carers', as such children are sometimes called, should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should **not** be assumed that children should take on, even at age 16 and 17, similar levels of caring responsibilities to adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities. Even in the small number of cases where a decision is made to support young people to care under the provisions of this Act, close monitoring of the situation should take place to ensure that the young people do not become fixed in their role as carer to the detriment of their education and future prospects. An assessment of family circumstances is essential. This will require good quality joint work between adult and children's social services as well as co-operation from schools and health care workers and the developing Connexions service.
- 76 The Government wishes to ensure that the person cared for is receiving sufficient services so that the young person is not undertaking an inappropriate caring role. In particular, assessment under the *Framework for the Assessment of Children in Need and their Families* will be aimed at ensuring that the child is not undertaking a level of responsibility that may undermine their ability to participate in education, including further and higher education, normal leisure

activities and social interaction with their peer group. Any such services provided will be designed **not** to support them in their caring role but rather to ensure that they do not undertake a caring role that is inappropriate.

- 77 Support should be aimed primarily at helping any adults with parental responsibility to carry out their parental role and to remove inappropriate responsibilities from children.<sup>4</sup> Care should be taken that children's development does not suffer through their undertaking too great a caring role. Assessing staff should not focus less on their needs as children because they have been labelled 'carers'. They should be allowed to be children, first and foremost.
- 78 In the case study above (Example 4), for example, caring may also have a significant impact on one or more of Teresa's children. Teresa's needs as a parent should be considered as part of the assessment as well as any consequences for her children.
- 79 It should be noted that the caring role is not necessarily one focused simply on caring tasks, such as personal care, moving and handling. Sometimes, as in mental health situations, the role may be to provide emotional support or intensive supervision rather than physical or personal care. Here too the impact of caring situations will differ with the age of the carer.

## Carers' Services

- 80 The Act provides new opportunities for authorities to be flexible and innovative in the way services are provided to people within caring relationships. As a guiding principle, authorities should be prepared to provide the most appropriate and cost-effective support to meet assessed needs. Much of the support that carers need may already be provided through the delivery of community care services. Focusing on the outcomes the carer and user want will help to ensure best value solutions. Anecdotally, carers sometimes say that they have approached councils to be told that they can have help with personal care (which they do not want) but not cleaning (which they do). In this context, local authorities that have decided not to provide or commission certain services as community care services – such as shopping only, cleaning only, or other low-level services – should review their positions. Such services, if targeted purposively, can be of genuine assistance in sustaining the caring relationship, and be cost effective.

---

<sup>4</sup> SSI report, Young Carers Something to Think About

- 81 Once it is clear that a cared for person or carer is eligible for support, it is crucial that the outcomes they want to see are discussed. Carer's services are not defined in the Act. The key is the outcomes the carer would value in terms of supporting them in their caring role and maintaining their health and well-being.

#### Example 5: Flexibility to support people in the way they want to be supported

*Edward and Ethel used to run a hotel. Edward is now very frail, but Ethel can still manage to care for him and they don't want home care which Edward would be eligible for but which they both regard as intrusive. However, Ethel **would** like help with cleaning. Having run a hotel, she is very particular about how the cleaning is done but she doesn't have time or energy for it now, because of looking after Edward. She expects the floors to be scrubbed and the furniture to be wet-dusted. A cleaning service is not normally provided by the local council. However, the care manager understands that the stress Ethel feels at not being able to manage to clean in the way she used to is undermining the sustainability of the caring situation.*

*Edward could have received a package of 10 hours per week homecare had he wanted it. Instead, Ethel is supported to manage a direct payment in lieu of a carer's service and is able to hire a cleaner for 3 hours per week. She achieves the outcome she most desires, and the care manager is reassured that her stress and workload are reduced, even though they have agreed that they will monitor the situation. The caring role remains sustainable for the foreseeable future and the new flexibilities allow a more cost-effective solution than was previously possible.*

- 82 In some situations cared for people will also be carers. A holistic assessment will identify their needs and the outcomes required in relation to both their roles.

### Example 6: People who are interdependent

*George, 30, has a learning disability. His mother Rose has been caring for him since he was born. She is now 72 and is becoming very frail. She is very worried about what will happen to George after she dies.*

*George is increasingly taking on housework and, partly as a result of his new responsibilities in the home, he has stopped attending his day service as regularly as he used to.*

*A holistic assessment, in effect a community care and a carer's assessment for each of them, reveals that both George and his mother now have caring roles. Both George and Rose agree that George should care for Rose, with the exception of the provision of intimate personal care.*

*Given his own disability the role George is taking on is deemed substantial and regular. The carer's assessment looks at the pair's interdependence and the strengths both bring to the relationship. It also acknowledges the positive contribution George is making to the smooth running of the household. However, he is starting to miss out on daytime activities so the care manager discusses with George and Rose whether, with this increase in his confidence, he might like to manage a direct payment to meet part of his social and leisure needs. This development of his independence skills also helps to make Rose feel better about the future.*

*A holistic approach to assessment allows the local council flexibility to deliver the best outcomes for them both. As both are community care users and carers the full flexibility of the legislation can be used to support both. Neither George nor Rose needs to be labelled in any way they do not wish.*

### Carers' services that may be delivered to cared for people

- 83 In certain circumstances, local councils may provide a service for the carer that takes the form of a service delivered to the person cared for. This flexibility is limited to services that could be provided to the person cared for by way of community care services (but see also paragraph 85 'Intimate services'). This may only happen if both the carer and the person cared for agree that the service is to be delivered in this way. Where the outcome the carer wants from their assessment would normally be provided through a community care service to the cared for person, but the cared for person refuses, the local council can now use its power to provide services for the carer, delivered to the cared for person.

### Example 7: Flexibility in relation to services 'either way'

*Jim is a substantial and regular carer for his mother Elsie who is frail and in the early stages of dementia. She is often incontinent. Elsie lives round the corner from Jim. Jim does all his mother's laundry.*

*There are various ways the local council may be able to help Jim.*

- a) *Elsie is eligible for community care support. If Elsie agrees to be assessed by social services, then a cleaning and laundry service could be provided as a **community care service** and delivered to her. Elsie would be the person financially assessed for any charges.*
- b) *If Elsie refuses to be assessed by social services (although she would be eligible for community care services) Jim could ask for a carers' assessment. The local council could agree to provide, as a carer's service, a cleaning and laundry service at Elsie's house. The local council would need to be satisfied that Elsie is prepared to tolerate the visits from these services. It turns out that so long as they don't bother her, Elsie will tolerate them. Social services arrange to pick the laundry up when Jim is at Elsie's home. This is a **carer's service provided for the carer (Jim), delivered to the cared for person (Elsie)**. Jim would be liable for any charge as the service is provided to help him in his caring role.*

*Jim and the care manager hope that Elsie will get used to people other than Jim coming round and may subsequently change her mind about being assessed and helped by social services.*

- c) *If Jim decides that the easiest way for him to cope with all this extra laundry is for him to have a new washing machine installed at his own home, he could then discuss with the care manager the provision of a direct payment so that he can buy one.*

*This would then be a **carers' service provided for the carer (Jim), delivered to the carer (Jim)**.*

*Jim would again be the person financially assessed in relation to any charges.*

- 84 It is likely that in most cases the preferred option would be to deliver services that could be delivered either to the cared for person or the carer as community care services where possible. In any case no services may be delivered to cared for people unless the local council are satisfied that the cared for person will accept them.

### *Intimate services*

- 85 Services provided for the carer but delivered to the cared for person must not be of an intimate nature. There are two possible exceptions to this. One is where the cared for person changes their mind and actually asks the person delivering the service to provide an intimate service. The other is where the cared for person is at risk of serious personal harm unless a service of an intimate nature is provided and he either cannot consent to it, or the person providing the service believes it is necessary to provide that service because the likelihood of serious personal harm to the person cared for is **imminent**.
- 86 The purpose of defining intimate services in regulations (see Policy Guidance paragraph 26) is to prevent such services being delivered to adults who are unwilling to receive them and whose rights would therefore be infringed. (If the cared for person was willing to receive intimate services in the first place, they would instead be assessed under community care legislation and receive community care services).

## Example 8: Ensuring intimate services are not delivered to adults who do not want them, except in emergencies

*John has a severe physical impairment. His wife Maureen cares for him, undertaking all his intimate personal care. He has always refused any form of help from the local council.*

*Maureen is desperate for some time to herself to see friends. She has received a carer's assessment from the council. She agrees with the care manager that the best way for her to get a break is for a home-care worker to provide a non-intimate sitting service, for three hours per week. John won't like it (even though the home-care worker will leave him to his own devices) but he will agree to have the home-care worker in the house and Maureen will enjoy her break knowing John is relatively safe.*

*One day the worker, Raj, hears John cursing and swearing. Raj realises that, while using the toilet, John has had an accident and is now dirty. Raj calls to John: 'Are you all right?' John tells him to mind his own business. Raj has no choice but to do just that, since John is not consenting to help and he is at no imminent risk. Although Maureen will be upset to find that John is dirty when she gets home, Raj cannot intrude on John's privacy without his consent.*

*A few months later, while Maureen is out, John falls from his chair. Raj hears the noise and calls to John: 'Are you all right?' John tells him to mind his own business, but this time it sounds like he is in real discomfort. Raj investigates. John is lying very near the electric fire. John again insists on being left alone. Raj turns off the electric fire so that John is safe until Maureen returns.*

*Again during one of Raj's visits, John falls out of his chair, this time on his side. Again he rejects help, but Raj has been told that in his current condition lying on his side could cause John to choke and he might therefore die if left. Raj goes into his room and lies him on his back so he is no longer in any danger. John is furious, so Raj provides no further assistance.*

- 87 For definitions of intimate services see Policy Guidance paragraph 26. In addition local councils should ensure that any service they are considering providing for a carer but delivering to the cared for person is not inappropriate in the context of the cared for person's cultural or religious beliefs, mental health needs, age, or family life and way of living.
- 88 Assessors will need to consider issues around how people may feel about, for example, having someone reading their post, coming into their prayer room, discussing their impairment or doing their laundry without their consent.

### Example 9: Service deemed intimate because of impact on mental health of cared for person

*Elaine cares for her son Toby 34 who has a psychotic illness. He is currently fairly well but refusing assessment or services. She has a carer's assessment. The outcome she wants is to have a break knowing that Toby and the house are safe.*

*A visiting service provided by a voluntary organisation is discussed. Unfortunately, the health professionals involved judge that such visits will worsen Toby's paranoia and would therefore have to be classed as an intimate service. Toby will tolerate visits from his brother, Andrew, but he lives in Scotland and lives on a very low income.*

*Therefore the solution developed with Elaine is for the local council to provide Elaine with a carer's service in the form of providing Andrew with a travel warrant so that Andrew can travel down and stay for a week. The only alternative would be a very expensive stay in a residential care unit which Toby will tolerate sometimes but doesn't enjoy.*

*Toby loves his brother and is looking forward to seeing him even though he resents the idea that anyone think he needs to be looked after. Because this carer's service has been designed to fit with Toby's mental health needs it avoids being classed as intimate.*

### Prescribed circumstances

- 89 Where a carer's service is delivered to the cared for person as a non-intimate service, there may be circumstances where the cared for person needs assistance other than that agreed to be delivered as part of the service contracted. Such circumstances will be by their nature unforeseen. However, there should be a degree of emergency planning. In each case it will be possible to envisage the type of support that might be necessary in an emergency and ensure that staff employed are able to provide appropriate support if required or requested.

### Example 9a: Prescribed circumstances where service becomes intimate

*Using the same example, if Toby did not experience paranoia, he might tolerate the visiting service from the voluntary organisation and the service could be deemed not to be intimate. Nevertheless, the service would need to be provided by staff with appropriate knowledge of Toby's condition.*

*Then, if, while the service was visiting (just to check Toby was all right and the house was secure and safe) Toby was found to have become very ill and started to hurt himself in his bedroom, it might be appropriate for the worker to enter the room and talk to him until more appropriate support services arrived to help.*

## Charges for services

- 90 It is for the local council to decide whether they are providing a service to support the carer's need (a carers' service delivered or arranged under the provisions of the Act) or a service to meet the care needs of the person cared for (a community care service). They may not, whilst assessing needs, take into account the likelihood of either party having the necessary means to pay any charges.
- 91 Once someone has been assessed as needing a service that service should not be withdrawn because the user or carer refuses to pay a charge. For further details related to charging see *Fairer Charging Policies for Home Care and other non-residential Social Services*, currently in draft for consultation, which will be published in May 2001.

### Example 10: Decisions about who is liable for any charges (see also Example 7)

*Maisie is blind and very frail. She is fiercely independent, and wants to continue living in her own home. She admits she gets a bit muddled over money so her daughter, acting as her agent, collects her pension and does all her shopping. Maisie is assessed as eligible for community care services. Her daughter June is happy to help her mother dress and undress, to continue to shop for her and help with a range of tasks so that her mother may continue to live in her own home. However keeping two homes clean is wearing her down. Maisie requests a cleaning service to relieve her daughter of this task which appears to be threatening June's own health and well being. This service could be provided as a community care service, and Maisie would be the person liable for any charge. However, Maisie is not keen on social services having a key to her house and does not want the responsibility of managing a direct payment so that she could employ a person of her own choosing.*

*June, Maisie's daughter and carer, as part of her carer's assessment identifies that it would work much better if she, June, could have a direct payment to purchase the services of a cleaner Elaine, whom Maisie knows and would trust with a key. Elaine can come and clean when June is at work providing her mother with some welcome additional company.*

*Maisie is quite happy to waive her entitlement to receive a service in her name. June understands that if the service is delivered to her as a carer's service that she will be eligible to pay any charges. She considers that in the circumstances this option for the delivery of a cleaning service meets her needs and the needs of her mother best. Direct payments to June are arranged.*

- 92 Information on charges for services and financial assessment should be clearly explained to all parties as part of the holistic assessment. Any financial assessment is entirely separate from assessment under s47 of NHS and Community Care Act 1990 or under the Carers and Disabled Children Act 2000.

## Direct Payments

- 93 Direct payments may, for some carers and people with parental responsibility for disabled children, be the key to accessing the support they require to enable them to continue in their caring role and to promote the welfare of their disabled child. Direct payments allow people to have control over how support services are delivered. They provide the degree of flexibility that may enable some carers to re-enter or continue in employment or education/training.

### *Assessment for a direct payment*

- 94 Once the carer's or the disabled child and family's needs have been assessed a discussion should follow on the most appropriate way for those needs to be met. One option for discussion will be a direct payment.
- 95 The Community Care (Direct Payments) Policy and Practice Guidance contains guidance on the assessment process for a direct payment. This guidance supplements the existing guidance for carers aged 16 or over caring for a person aged 18 or over and people with parental responsibility for a disabled child.
- 96 Local councils have the discretion to refuse direct payments to anyone whom they judge would not (with the appropriate support) be able to manage them. The judgement as to whether someone is able to manage will need to be made on an individual basis, taking into account the views of the individual him or herself.
- 97 The decision about whether someone is able to manage a direct payment should be made with regard to the degree of management required. For instance the ability to manage a large support package requires a different level of management than the ability to manage a direct payment for a few hours of low-level domestic help.
- 98 People who receive direct payments may also find it helpful to have access to advocacy support. A support service may also be well placed to act as an advocate for local users as a group when the local authority is considering changes to the scheme, but it may well be preferable to separate any support role from advocacy role on behalf of individuals, to avoid any conflict of interest.

## *Information and Support Services*

- 99 Local councils should already be providing information about their local direct payment scheme and have in place support services for current eligible groups of direct payment recipients. Councils will wish to build on their current expertise about best practice in the provision of such information and support services so that the infrastructure supporting the local direct payment scheme is flexible enough to meet the needs of :
- carers
  - young carers
  - people with parental responsibility for a disabled child or children.
- 100 The Community Care (Direct Payments) Policy and Practice Guidance 1996 provides guidance on providing information and setting up support services for direct payments users.

## *Adult carers caring for another adult*

- 101 Carers may only receive direct payments for carer's services they themselves have been assessed as needing. They may not receive a direct payment for the community care services that are delivered to the person they care for. Direct payments will still offer carers flexibility in how the support they receive to help them in their caring role or to maintain their health and well-being is delivered.

### Example 11: Using Direct Payments to deliver outcomes carers want

*Sue 37, cares for her husband David who has had a stroke. Sue lives a long way from the shops. Using public transport makes Sue's life very difficult. While she is out David is on his own, but he does not want anyone but Sue to care for him and he doesn't want to use day services.*

*This means there is always pressure on Sue to get back quickly.*

*David used to drive until he had his stroke. David owns a car, but Sue cannot drive.*

*Talking with Sue about the outcomes she would want to see, the care manager realises that support to get around would be the most important help for her.*

*Following discussion, it is clear that Sue would be willing and able to manage a direct payment. Initially it is envisaged that she would spend this on taxi fares. However Sue decides the best use for the money for a period of time would be for her to buy some driving lessons.*

## Young Carers

102 There will be few situations where a direct payment is the most appropriate way of delivering services to a 16 or 17 year old carer who is caring for someone aged 18 or over. A direct payment could provide such a young carer with greater choice and control over how their own support needs are met. At the same time direct payments bring with them additional responsibilities which are potentially a burden to a child already burdened with such caring responsibilities. One example where the benefits outweigh the burden might be where a young carer is contributing to the care of a terminally ill loved one but wishes to continue in full time education; a direct payment may provide the flexibility that enables them to achieved their preferred outcome.

## Example 12: Direct payments for 16 and 17 year old young carers

*Janet is 45. She cares for terminally ill husband, Joe. Up to now he has refused to have anyone care for him but family members. His condition is worsening. Janet is desperately trying to keep her job, and, as it is the summer holidays her three children, Colette 13, Noel 15 and Ben 17 are taking on much of the caring during the working day.*

*Janet is worn out, stressed and anxious. She approaches social services, even though Joe is furious with her, because she is so very concerned about the impact of looking after Joe without outside help on Noel, Colette and Ben. Janet has an additional concern: how they will all manage if she loses her job.*

*The assessor undertaking an initial assessment is confident that Joe is eligible and that Janet is a substantial and regular carer.*

*He is also aware of the local council's responsibilities under the Children Act 1989, so he involves a Children and Families professional in the holistic assessment process.*

*The holistic assessment of the situation leads to the provision of home-care and hospice-at-home service for Joe, which he reluctantly accepts because the assessment process has helped him to think more clearly about the impact of his condition on his children.*

*Colette and Noel are assessed as children in need. Services are provided to make sure that they can go away for a break with their mother, meet other children in similar situations for mutual emotional support, and get back in to the swing of ordinary leisure activities with their peers with whom they have lost contact..*


*Ben, however, expresses a very strong wish to carry on being involved in the care for his father until he dies, minimising the impact on his father of care provided by 'outsiders'. As Ben is 17 and the assessors believes it would be in his best interests to be allowed to continue in his caring role, Ben is assessed under the provisions of the Carers and Disabled Children Act support him in his caring role, rather than simply to reduce it.*

*Ben and his father have always been close and share an enthusiasm for modern art. Ben has taken a year off from Education to care for his father. In lieu of a carers' service to help him engage in leisure activities, which everyone agrees he needs, he opts for direct payments. When his father is being cared for by home-carers or nurses (community care services), he uses these direct payments for trips to art galleries, all of which he discusses at length with his father on his return. Ben is hoping to go to Art College in due course. Ben is pleased to receive advice from the direct payment support service about direct payments.*

- 103 When assessing whether the young carer is willing and able to manage the direct payment the local council should consider the impact of the additional responsibility direct payments will bring and be satisfied that this will provide the best possible outcome for the young carer. However, the local council should consider how the young person could be supported to manage any direct payment. For instance, the young carer would need to be informed that they could have the payroll aspects of managing a direct payment dealt with by a local payroll service.

### *Connexions*

- 104 Social Services departments should develop appropriate links with educational services and specifically with the developing Connexions service. The aim of this service is to give every young person the best possible information, advice, guidance and personal support through their teenage years to help them succeed in learning and prepare for their adult and working life.



## Part IV Practice Guidance People with parental responsibility for a disabled child

105 Direct payments for people with parental responsibility for a disabled child will enable parents themselves, following an assessment of the family's needs, to purchase services of their choosing to meet those assessed needs. Following an assessment it may be decided that the family should receive support to care for their disabled child. The local council could offer a weekend break for the disabled child every other weekend or a direct payment for the cost of this service. The family may choose to employ someone for a couple of hours a few nights a week to look after their disabled child while they spend time helping their other children with their homework or taking them to after school clubs. During school holidays, the parents might choose to use their direct payment differently. For example, on one residential break for their disabled child while they holiday with their other children, or on employing a personal assistant who will holiday with the whole family taking responsibility for much of the caring role, so that the whole family may enjoy time together.

### *Employing a suitable person*

106 The Care Standards Act 2000 contains provisions that ensure local councils have to undertake criminal record checks on behalf of parents using direct payments to employ someone to care for their child if the parent wishes. Details of how these provisions will operate when the Criminal Records Bureau is established are set out in paragraphs 59 to 62 of the Policy Guidance. Currently local councils if requested to do so by a parent may apply direct to the Department of Health for a check against the Protection of Children Act list to be undertaken. No fee will be payable. In addition until such time as the Criminal Records Bureau is established local councils will wish to continue their present arrangements for seeking criminal records checks.

107 The Care Standards Act 2000 enables a person who is considering employing an individual to care for their child, where that care is funded by a direct payment, to ask the local council to carry out checks under the Protection of Children Act via the Criminal Records Bureau. When the person with parental responsibility

requests such a check the local council has a duty to comply.

- 108 An individual wishing to work with the child will make the application for a check to be carried out. The application will be counter-signed by the local council. A fee is required for each background check. The individual making the application for employment will normally be asked to pay the fee. The local council may wish to consider the cost of the check in its estimate of the reasonable cost of securing the provision of the service so that the direct payment user may reimburse successful candidates.
- 109 Local councils may want to clarify with those who request a check that it is in the council's discretion whether or not to make a direct payment. A parent's insistence on employing an individual who has been found to be unsuitable following such a check will be a factor in the council's decision whether to exercise its discretion.
- 110 Local councils should make people with parental responsibility aware that the fact that a check reveals no criminal convictions does not necessarily mean that someone is a suitable person to work with children. They should still offer the advice below (paragraph 112).

### Advice to parents wishing to employ someone to look after their child

*Information should be clear and straightforward about the risk of child maltreatment without unnecessarily raising anxieties. The information could cover the following advice:*

*Be suitably cautious. If they have any doubts about the person they should not take them on.*

*Take note and listen to everything that your child is communicating about the care they receive. Especially with non-verbal children note should be taken of unusual or regressive behaviour.*

*Always ask for two references and check these carefully - following up with a phone call is often advisable.*

*Ask all the questions that are important to you, for example about where the child might be taken, other members of the household, and eating and smoking habits.*

*Ask to speak to other parents who have employed the individual concerned.*

*If choosing to ask for a criminal records check, to ensure that such check has been completed recently/in the last month.*

*Try and spend time ensuring that your child is able to settle with the new person.*

*Do not employ person until you feel assured that he or she has the best interests of your child at heart.*

*Do not employ someone under the age of 16 to undertake a paid caring role as people under 16 may not be mature enough for such a responsibility.*

### **Example 13 : parent using direct payments where there may be child protection and/or child safety concerns**

*Margaret cares for Kieran who has Smith Magenis syndrome. Kieran has very limited verbal communication, and needs constant supervision. Social Services have organised short break care, so that Kieran is reviewed as a 'Looked after child'. He also attends an Out of School club.*

*The staff at the Out of School club tell Kieran's social worker about a number of bruises on his legs. In discussion with Margaret, the social worker finds that Margaret is leaving Kieran in his bedroom so she can do housework. Kieran bruises his legs when he tries to climb over the safety gate.*

*The social worker arranges for a carer's assessment, and Occupational Therapist advice on safety in the home. Margaret wants to spend more time with Kieran and her other child. Her carer's assessment includes domestic help three times a week to give her more time with the children, and she will use the direct payment to employ Jean, a woman who is quite well known in the neighbourhood. Margaret wants to continue to use Social Services for Short Breaks.*

*Margaret is grateful for the advice about safe employment practice. Jean understands the need for background checks. Margaret asks the local council to carry out these checks.*

- 111 When parents have chosen to ask for a check to be carried out, they should be advised to continue to receive services from their local council or current provider, or, in the interim, contract with a registered agency for the services they need to meet the assessed needs of the disabled child and family until the prospective candidate for employment is approved.
- 112 In all situations where people with parental responsibility for a disabled child are considering employing a person to help look after their child, the local council should emphasise the importance of employing a suitable person and provide information, advice and support to do so. A checklist such as that available on [www.chilcarelink.gov.uk](http://www.chilcarelink.gov.uk) that enables parents to select safe childcare may be helpful.
- 113 Local councils may also make available the list of registered child minders and other registered providers of childcare in the area. The local council may consider that the direct payments support service is well placed to provide information and support to the person with parental responsibility for a disabled child.

### *Direct Payments as part of a package*


- 114 A direct payment need not be used to meet all the assessed support needs of the family. Where the local council is providing a satisfactory service the person with parental responsibility of a disabled child may want that part of the package to be provided direct by social services. Local councils and people with parental responsibility of a disabled child will need to keep in mind that when disabled children reach age 16 or 17 they may want to take advantage of the opportunity to manage their own personal support needs via a direct payment. People with parental responsibility for a disabled child may wish to consider sharing and gradually relinquishing responsibility for the management of part or all of the care package. For example the disabled child may wish to manage a portion of the direct payment to purchase support to allow them to attend an after school theatre club.

### *Transitional arrangements for people with parental responsibility for disabled children*

- 115 Transition from children's to adult services requires close collaboration and clear understandings between the different divisions of a Social Services Department. Plans should be made in partnership with parents, valuing their experience and knowledge, and with disabled young people, giving due weight to their wishes and feelings. Local councils will need to ensure that people who have parental responsibility for a disabled child are clear about the changes that will take place in the way services are delivered to them as carers once the young disabled person reaches 18. For example, that they may not continue to receive direct payments to purchase any services that young person is assessed as needing under community care legislation. See paragraph 75 of the Policy Guidance. In addition, that if they are going to continue in their caring role, that they may be entitled to receive carers' services under the provisions of the Act.
- 116 To receive carers' services once their child reaches 18, parents will need to have their support needs reassessed. For further guidance about carers' services for people caring for someone in receipt of community care services see paragraph 80.

### *Deciding how direct payments are to be used, calculating the amount of the direct payment and making the payment*

- 117 There may be disagreements about whether basic care the child has been assessed as needing constitutes nursing or social care or is part of their education (and therefore which agency should pay). These disagreements must be resolved before making a direct payment and decision reached in the same way as decisions about the provision of support to meet an assessed need by the means of local council services. Identifying these barriers is an appropriate focus of assessment. Further guidance on assessment for a direct payment, deciding how they are to be used, calculating the amount making the payment, monitoring and reviews and can be found in the Community Care (Direct Payments) 1996 Policy and Practice guidance.



If you require further FREE copies of this publication please contact:

Department of Health Publications  
PO Box 777  
London SE1 6XH  
Fax: 01623 724524  
E-mail [doh@prolog.uk.com](mailto:doh@prolog.uk.com)

Please quote reference xxxxxx when ordering.

It is also available on our website at:  
[www.carers.gov.uk/zone9.htm](http://www.carers.gov.uk/zone9.htm)

This publication can also be made available in braille, on audiocassette tape, by email, on disk, in large print, and in other languages on request.

The text of this document may be reproduced without formal permission or charge for personal or in-house use.



First Published: March 2001

© Crown Copyright  
Produced by the Department of Health  
00000 1P 4k Mar 01 (00)  
CHLORINE FREE PAPER