CARERS AND THEIR RIGHTS
This guide describes the legal rights of carers as they apply in England and Wales.

It has been published by Carers UK and the Action for Carers and Employment (ACE National) Development Partnership.

About Carers UK

Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

Carers UK is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers’ contribution to society and carers get the practical, financial and emotional support they need.

Carers UK is here to improve carers’ lives. We achieve this by
- Campaigning for the changes that make a real difference for carers
- Providing information and advice to carers about their rights and how to get support
- Training professionals who work with carers
- Mobilising carers and supporters to influence decision-makers
- Gathering hard evidence about what needs to change
- Transforming the understanding of caring so that carers are valued and not discriminated against

About ACE

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Foreword
I am proud to have sponsored the Carers (Equal Opportunities) Act 2004 and to have worked with Carers UK and the Action for Carers and Employment (ACE National) Partnership to achieve its successful passage through Parliament. Our next challenge is to support its effective implementation by local authorities and I believe this guide to carers’ rights will be an invaluable platform for that support.

Dr Hywel Francis
MP for Aberavon
1.1 This guide outlines the principal rights of carers to support from the health and social services authorities. Its publication coincides with the coming into force of the Carers (Equal Opportunities) Act 2004 in England and Wales.

1.2 This guide does not seek to address carers’ entitlement to welfare benefits – but at para 8.1 links are given to information sources where this information can be obtained.

1.3 The Carers (Equal Opportunities) Act 2004 introduces an important new dimension to carers’ support services, not least in seeking to assist those carers who wish to work or who wish to access education, training or leisure activities.

1.4 The 2004 Act marks a major cultural shift in the way carers are viewed: a shift in seeing carers not so much as unpaid providers of care services for disabled people, but as people in their own right: people with the right to work, like everyone else: people who have too often been socially excluded and (like the disabled people for whom they care) often denied the life chances that are available to other people. The depth of these difficulties can be highlighted by three simple statistics:

- Carers lose an average of £9,000 pa by taking on significant caring responsibilities¹.
- Over half of all carers have a caring related health condition².
- Carers represent one of the most socially excluded groups of people – for whom the Government’s inclusion policy appears (to date) to have failed³.

1.5 The 2004 Act, accordingly, requires social and health care professionals to re-orientate their approach to carers. It is an Act that will, in time bring about major cultural change in relation to such perceptions. In due course it will need to be strengthened by more robust legislation: legislation to outlaw discrimination against carers and legislation imposing specific responsibilities on the NHS to promote the health and well being of carers.

1.6 In relation to the issue of discrimination, it is extraordinary that an employer has no duty to make reasonable adjustments to enable a carer to remain in employment. It is conceptually difficult to see the difference between a carer who, due to his caring responsibilities has to ‘clock-in’ at work 30 minutes after the normal starting time – with that of a disabled person who due to her impairments cannot make the same deadline. For one the law provides protection from dismissal in such a case and for the other it does not (but see however para 4.68 below).

1.7 In relation to the need for a specific NHS obligation to carers the above statistics tell
their own story. If there are in excess of 6 million carers in the UK and if over half of them suffer ill health as a consequence of their caring responsibilities – then by any stretch of the imagination this is a major health concern.

1.8 This guide focuses on three Acts of Parliament – each of which is directly concerned with the needs of carers. Each Act started life as a Private Members Bill.

- Carers (Recognition & Services) Act 1995, promoted by Malcolm Wicks MP
- Carers & Disabled Children Act 2000, promoted by Tom Pendry MP
- Carers (Equal Opportunities) Act 2004, promoted by Dr Hywel Francis MP

REFERENCES

1 Caring Costs, 1996, *op cit*.


WHO IS A CARER?

2.1 There is no single definition of a ‘carer’. The law makes reference to carers in many contexts. In general, when a social services department is deciding what services to provide for a disabled person, it should consider the views of significant people in that person’s life. This will include people who provide some form of care for that person (usually family members or friends or neighbours) be that physical care or emotional support, advice or advocacy support etc. In this guide a carer is a person who provides care to another person and is not paid for providing that care (nor is she or he providing the care as a volunteer placed into the caring role by a voluntary organisation).

2.2 Some academic writers have used the term ‘informal carer’ to distinguish actual carers from care workers who are often wrongly described as carers. Many carers actively dislike the term, seeing nothing informal about caring for substantial amounts of time. The term is not therefore used in this guide.

CARE WORKERS AND VOLUNTEERS

2.3 The Carers Acts do not provide rights to persons who provide the care by virtue of a contract of employment or as a volunteer for a voluntary organisation. If a disabled person uses a community care direct payment to employ his or her carer, then the carer’s entitlement to a carers’ assessment would cease (although the authority would retain discretion to assess in any event).

CARERS WITH SUBSTANTIAL CARING RESPONSIBILITIES

2.4 Whilst the views of all carers are relevant when social services or the NHS are making decisions about the needs of a disabled person – certain carers are entitled to additional assistance from social services departments. These are carers who ‘provide or intend to provide a substantial amount of care on a regular basis’. Such carers have a statutory right to a ‘carers’ assessment’ and in certain situations to support services from the social services department. The meanings of ‘substantial’ and ‘regular’ are considered at para 3.18 below.

DISABLED PERSON

2.5 A carer is defined by reference to his or her caring role in respect of a ‘disabled person’. The law defines disabled people (for the purposes of carer and community care legislation) as persons who are:

blind, deaf or dumb or who suffer from a mental disorder of any description, and other persons aged eighteen or over who are
substantially and permanently handicapped by illness, injury, or congenital deformity

2.6 It follows that anyone with a mental disorder (for instance depression or dementia or a learning disability etc) is considered by the law to be a disabled person.

2.7 There are some people who may be on the borderlines of this definition. People who have drug or alcohol related problems are considered to be disabled people for the purposes of carer and community care law and people with Chronic Fatigue Syndrome (sometimes referred to as ME) would also generally be considered to fall within the definition. Children with hyperactive and attention deficit disorders (sometimes referred to as Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD)) should – if professionally diagnosed as having such a disorder – be considered to be within the definition. Even if there is no such diagnosis, such children would fall within the definition of a ‘child in need’ (see para 10.6 below). The same would be the case for a child diagnosed as having a milder form of Asperger’s syndrome.

2.8 In practice many local authorities have unlawful policies which deny support to families caring for children with disorders such as ADHD.

SOCIAL SERVICES

2.9 This guide is predominantly concerned with the obligations of certain types of local authorities towards carers. For the sake of brevity this guide uses the phrase ‘social services’ (or social services departments) when referring to these authorities. In general these authorities are County Councils, London Borough, Metropolitan Borough and Unitary Councils – ie not District Councils. The use of the phrase ‘social services’ is no longer strictly accurate, since such authorities are undergoing a restructuring (as a consequence of the Children Act 2004). In due course they will have two directors (in place of the one ‘Director of Social Services’ at present) – these being known as the Director of Children’s Services and the Director of Adult Social Services. However, rather than referring throughout to ‘Adult Social Services and Children’s Services Departments’ for the sake of brevity the generic phrase ‘social services’ is used in this guide.

REFERENCES

4 Section 1(3) Carers (Recognition and Services) Act 1995 and s1(3) Carers and Disabled Children Act 2000).
5 There are significant differences between this definition and the legal definition of a ‘disabled person’ for the purposes of disability discrimination law (ie in relation to employment, access to services, transport, and so on).
6 Section 29 National Assistance Act 1948.
7 Schedule 8 National Health Services Act 1977.
3. Social services obligations to Carers – overview

INTRODUCTION

3.1 Since 1986 when carers were first mentioned in social care legislation⁸ their official recognition has grown dramatically. In the first 15 years this recognition took the form of initiatives designed to sustain their caring role. In the last 5 years, however carers have increasingly been seen as people who are entitled to direct support rather than being of only indirect relevance. Many carers are severely socially excluded, suffer from caring related ill-health and once they have ceased caring find themselves in a parlous economic position and frequently without any pension provision.

3.2 It is for this reason that the Carers (Equal Opportunities) Act 2004, the Work and Families Act 2006 and the Childcare Act 2006 seek to challenge the social exclusion experienced by carers – particularly through the promotion of their employment, training, education and leisure opportunities. This trend is likely to be reinforced by changes to the auditing regimes.

3.3 The Commission for Social Care Inspection in its 2006 Consultation Paper aims to place carers at the centre of adult care social services strategy⁹: making carers a core client group. If implemented the proposals would grade local authority performance to reflect activity and expenditure considerations for 5 separate client groups:

- Older People 40%
- Carers 15%
- People with Learning Disabilities 15%
- Mental Health 15%
- Physical and Sensory Disability 15%

3.4 Notwithstanding this increased emphasis on carers’ support at the strategic planning level, the evidence suggests that this is not translating into support ‘on the ground’. In its ‘State of Social Care on England Report (December 2006)¹⁰ the CSCI noted that

Carers’ responsibilities are increased by the trend towards ever-tighter eligibility criteria for access to services. Support for unpaid carers remains one of the biggest public policy challenges of our time. ... [and] ..... services for carers remain patchy and limited, and that in many areas carers still do not have the same opportunities as other people. Carers continue to tell us that they only receive support when they reach crisis point, when what they need most is flexible respite care and sustained support.

OVERVIEW OF CURRENT RESPONSIBILITIES

3.5 All carers have certain basic rights: largely a right to have their views taken into account by a social services department when it is considering how best to make provision for a disabled person.
3.6 Carers that provide, or intend to provide a ‘substantial’ amount of care on a regular basis have additional rights, in that they are entitled to have a separate ‘carers assessment’.

3.7 In most cases, the role and views of a carer will be considered by the social services department when it is undertaking an assessment of the disabled person. Section 6 below briefly outlines the key components of a community care assessment – i.e. the assessment that social services departments undertake when deciding what support it should provide for a disabled person.

THE RIGHTS OF ALL CARERS

3.8 As noted above, all carers (regardless of whether they provide, or intend to provide, regular and/or substantial amounts of care) have the right to have their views taken into account by a social services department when it is considering how best to make provision for a disabled person.

3.9 The law states\(^\text{11}\) that that when undertaking a community care assessment, social services must (amongst other things):

- Consider whether the person has any carers and, if so, also consult them if the authority “thinks it appropriate”

- Take all reasonable steps to reach agreement with the person and, where they think it appropriate, any carers of that person, on the community care services which they are considering providing to meet his needs

3.10 In this respect, important policy guidance\(^\text{12}\) issued by the Department of Health in 1990 advised that community care assessments and care plans must take account of the disabled person’s and the carer’s own preferences and that they ‘must feel that the process is aimed at meeting their wishes’.\(^\text{13}\) The guidance emphasises that the ‘preferences of carers should be taken into account and their willingness to continue caring should not be assumed’ and that the disabled person’s ‘care plan should be the result of a constructive dialogue between service user, carer, social services staff and those of any other agency involved’.\(^\text{14}\)

CARERS WHO PROVIDE A SUBSTANTIAL AMOUNT OF CARE ON A REGULAR BASIS

3.11 In addition to having their views taken into account, when the person for whom they care is being assessed, certain carers have the right to a ‘carers assessment’. These are carers who provide (or intend to provide) a substantial amount of care on a regular basis. Such carers can refuse an assessment – but even if they do so, the law requires that their ‘ability to manage’ their caring role must nevertheless be taken into account\(^\text{15}\) – and the fact that they have refused such an assessment should not be ‘used as a reason to exclude the carer from assisting with care planning’.\(^\text{16}\)

3.12 Three different statutes regulate the nature and outcomes of a carer’s assessment. These are:

- The Carers (Recognition & Services) Act 1995

- The Carers and Disabled Children Act 2000

- The Carers (Equal Opportunities) Act 2004
The above links provide access to the texts of the Acts, as worded when enacted. The 1995 & 2000 Acts have since been amended by the 2004 Act.

3.13 Of the three Acts that deal directly with the needs of carers, the 1995 Act contains the core statutory responsibilities. It introduced the concept of ‘carers’ assessment’. The 2000 Act extended the rights of carers, to include the right to support services, and for these services to be made available by way of direct payments and ‘vouchers’. The 2004 Act extended the obligations in relation to assessments. It introduced (1) a statutory obligation on social services to inform carers of their rights and (2) requires carers assessments to consider whether the carer works or wishes to work and / or is undertaking, or wishes to undertake, education, training or any leisure activity.

 GUIDANCE

3.14 Guidance has been issued in both England and Wales concerning the implementation of the three Carers Acts. Social services guidance comes in two forms – ‘policy guidance’ which is often termed ‘binding’ guidance as it instructs authorities as to what they must do, whereas ‘practice guidance’ is advisory suggesting the steps that authorities might take in order to implement the legislation. The fact that practice guidance is advisory does not mean that it can be ignored. If an authority decides not to follow practice guidance it will generally be required to provide cogent reasons for such a decision and the greater the departure, the more likely it is that the Court or Ombudsman would find such action impermissible.

 GUIDANCE ON THE 1995 ACT

3.15 The first guidance concerned the 1995 Act. Both policy and practice guidance was issued concerning this Act and although published separately in Wales by the then Welsh Office, it was in the same terms as the English guidance. This guidance can be accessed via the carersnet website at www.carersnet.org.uk/acts/acts.html. In England the guidance was given the reference LAC (96)7 and in Wales its reference is WOC 16/96 and WHC (96)21.

 GUIDANCE ON THE 2000 ACT

3.16 A variety of guidance was issued concerning the 2000 Act, both in England and in Wales, of which in England the most important was practice guidance issued as ‘Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance’. Similar (but slightly shorter) guidance appeared in Wales as ‘Guidance 2000 Act’. In addition guidance was issued in both England and Wales (in very similar terms) concerning the Carers assessment process. The English guidance can be accessed at www.carers.gov.uk/carersdisabledchildact2000.htm and the Welsh at www.wales.gov.uk/subicarersnew/content/guidanceforcarers.pdf. Both are referred to throughout this Guide.

 GENERIC 2004 GUIDANCE

3.17 In 2004 combined policy guidance was issued by the Department of Health concerning both the 2000 and 2004 Acts. In addition and most importantly practice guidance on the 2004 Act was issued by the Social Care Institute for Excellence (SCIE). In Wales no guidance on this Act has as yet been issued although in anticipation of the implementation of the Act an additional
annex (12) to the Unified Assessment Process (see para 6.2 below) was issued to strengthen the practice obligations in Wales to provide separate carers’ assessments.

WHAT IS ‘A SUBSTANTIAL AMOUNT OF CARE’

3.18 As noted above, people who provide (or intend to provide) ‘a substantial amount of care on a regular basis’ are entitled to a separate carer’s assessment. None of the Carers Acts defines what is meant by the word ‘substantial’ and so to a degree the decision rests with individual social services departments – albeit that in deciding how to interpret this phrase, authorities must take into account the relevant guidance.

3.19 As the guidance notes, it is of course possible that ‘there may be more than one carer providing substantial and regular care in each household’.19

3.20 The Department of Health has elsewhere given advice on the interpretation of the word ‘substantial’ where it appears in a community care statute – and advised that it should be given a wide interpretation which fully takes into account the individual’s circumstances20. Essentially, therefore, that the word should be used subjectively, and this must also be the case in the context of the Carers Acts.

3.21 Local authorities will, therefore need to adopt a flexible approach to this question and focus on the ‘impact of caring’. It follows that what may not be a substantial amount of care to a 25-year-old carer may be otherwise if provided by a seven or 87-year-old carer. Likewise if the caring task is physically demanding, then the question of what is or is not substantial will depend in part on the physical strength of the carer; again, if the carer has recently recovered from a serious mental illness, then even five hours care may be substantial to him or her. A morning or evening caring task will be substantial to a carer who works nine to five but not necessarily for one who does not – and so on.

3.22 Practice guidance issued under the 2000 Act is particularly helpful in defining what ‘regular and substantial’ care means. The English guidance21 at para 67-8 (the Welsh guidance at para 4.11)22 states:

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 lifelong 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?
3.23 The assessment of the ‘sustainability of the caring relationship is further considered at para 4.28 below.

‘INTENDING TO PROVIDE’

3.24 A carer may be entitled to a carer’s assessment even if s/he is presently providing no care – provided the authority is satisfied that s/he is intending to provide a substantial amount of care on a regular basis. The intent underlying this provision was explained by the guidance that accompanied the Carers (Recognition and Services) Act 1995, LAC (96) 7 (at para 16):

By including carers both providing or intending to provide care, the Act covers those carers who are about to take on substantial and regular caring tasks for someone who has just become, or is becoming, disabled through accident or physical or mental ill health. Local and health authorities will need to ensure that hospital discharge procedures take account of the provisions of the Act and that carers are involved once planning discharge starts.

DISPUTES AS TO WHETHER A CARER PROVIDES ‘SUBSTANTIAL’ AMOUNTS OF CARE

3.25 As noted above, all carers – regardless of whether or not they provide regular and substantial amount of care – are entitled to have their views taken into account during the community care assessment process (see para 3.8 above).

3.26 Whilst a social services department is under a duty to undertake assessments of carers who provide regular and substantial amount of care, it also has a power to assess carers even if their caring responsibilities are not deemed ‘substantial’. In many cases good practice will dictate that such an assessment be undertaken in any event.

3.27 Not infrequently, a local authority will not be able to decide upon the extent of a carer’s responsibilities without undertaking a carer’s assessment. Where there is uncertainty an assessment should take place. The Local Ombudsman has been highly critical of a local authority that refused to undertake a carer’s assessment in such a case, commenting 23:

It should also have been obvious to the Council that a carer’s assessment was necessary in order to see (a) how much support [the carer] could reasonably be expected to provide for his brother without placing his own health at unacceptable risk; and (b) what practical help could be provided to [the carer] with respite from his caring responsibilities.

WHAT IS ‘A REGULAR BASIS’

3.28 Carers who provide a substantial amount of care, are entitled to an assessment provided that they also do so on a ‘regular basis’. In this context, ‘regular’ should be distinguished from ‘frequent’; it merely connotes an event which recurs or is repeated at fixed times or uniform intervals.21 The Practice Guidance to the 1995 Act 24 points out that:

Some users with mental health or substance misuse problems or with conditions such as neurological disorders, dementia, cancer or HIV/AIDS will have care needs which vary over time but may present regular and substantial burdens for carers.

3.29 It follows that an ongoing severe but sporadic caring responsibility would meet the criteria of “regular and substantial” since it amounts to a “regular concern.
REFERENCES

8 Section 4 Disabled Persons (Services, Consultation and Representation) Act 1986.


11 The Community Care Directions 2004, accessible at www.dh.gov.uk/assetRoot/04/08/84/77/04088477.pdf

12 Community Care in the Next Decade and Beyond (HMSO 1990).

13 Para 3.25 and 3.16 of the above guidance

14 Para 3.28 of the above guidance.

15 Section 8 Disabled Persons (Services, Consultation and Representation) Act 1986


17 For a detailed explanation as to the legal status of guidance, see L Clements (2004) Community Care and the Law chapter 1.

18 SCIE practice guide to the Carers (Equal Opportunities) Act 2004 accessible at www.carers.gov.uk/whatsnew.htm. The Guidance, although issued by the has the status of department of health practice guidance: see statement Liam Byrne Parliamentary Under Secretary of State for Care Services House of Commons Hansard 11 Jul 2005 Column 722W.


22 Accessible at www.wales.gov.uk/subicarersnew/content/guidanceforcarers.pdf

23 Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004.

24 Para 7 practice guidance LAC (96)7 and WOC 16/96 and WHC (96)21 in Wales.
4. The carer’s assessment

THE CARER’S ASSESSMENT PROCESS – IN A NUTSHELL

When a disabled person is being assessed (either under the Community Care legislation or the Children Act) [but see para 9.2 below] and their carer requests an assessment, the process should proceed as follows.

1. The information about the 'presenting needs' of the disabled person should be gathered in the normal way – ie all those needs that s/he (and those close to him/her) identify as existing as well as those that the assessor also identifies.

2. Before the assessor decides which of the disabled person’s various needs 'call for the provision' of social care services by the local authority, the carer should have their assessment.

3. The carer's assessment analyses the sustainability of the caring role – primarily whether the carer is willing and able to carry on caring and/or providing the same level of care. The risks to sustainability can include health risks to the carer, their wishes to remain in work or return to work or undertake training, education or leisure activities and so on.

4. Once the assessor has completed the carer’s assessment, s/he will then be in a position to decide what services should be provided to the disabled person and (if needs be) what services might be provided to the carer (ie services under the Carers and Disabled Children’s Act 2000 or the Children’s Act 1989).

5. The assessor should then draw up a care plan explaining how the disabled person's needs will be met (ie by identifying the services the local authority will provide) and how the carer's needs will be met (either by providing additional services to the disabled person – eg a sitting service) or (less commonly) by providing actual services to the carer.
WHICH SOCIAL SERVICES DEPARTMENT IS RESPONSIBLE?

4.1 Social services departments have a general duty to assess certain carers, when requested so to do. However it may not always be clear which social services department is actually responsible for undertaking the assessment. The practice guidance to the Carers and Disabled Children Act 2000, gives guidance on boundary problems; where the carer lives some distance away from the user. It advises that in general it will be the disabled person’s home authority (not the carer’s) which will be responsible for the assessment and the provision of any services under the 2000 Act.

DELEGATION OF ASSESSMENTS

The duty to assess under the Carers Acts is a social services function and which cannot be delegated unless (and unusually) the authority has entered into a formal partnership arrangement with an NHS body under s31 Health Act 2001 s31. The general position is explained by the Combined Policy Guidance under the 2000 and 2004 Acts (at para 45):

*A local authority may contract with another body to carry out part of the assessment process on its behalf, for example interviewing the carer, researching possible assistance, preparing a report and even making a recommendation. However, as an assessment is a statutory function of the local authority it will have to make the final decision about whether or not to provide services itself. It is not enough for the local authority to simply check on a complete or partial basis the outcomes of another organisation’s assessments.*

THE CARER MUST REQUEST THE ASSESSMENT

4.3 The right to a carer’s assessment is triggered once a carer has requested that one take place. This should be carried out as soon as reasonably practicable or immediately in an urgent case. This is in contrast to a disabled person’s community care assessment – which is not triggered by a request but ‘by the appearance of need’. Of course the ability to request an assessment depends upon knowing such a right exists. There is accordingly a duty on social services to inform carers of their right to make such a request. This right is considered under the next heading ‘the duty to inform’.

THE DUTY TO INFORM

4.4 Although carers consistently rate the provision of information as one of their top priorities, research suggests that almost half of them are not even advised of their right to an assessment when the person they care for is being assessed. A 2003 Department of Health Social Services Inspectorate report reinforces this concern, finding that carers ‘were not consistently offered a separate assessment of their needs’.

4.5 Although there are approximately six million carers in the UK at any one time, what is not generally appreciated is that this is a rapidly changing group of individuals with approximately 2 million adults becoming (and ceasing to be) carers every year. This means that at any one time the impact of caring will affect very many more than the six million – ie additionally the 2 million that have recently ceased caring and the 2 million that are about to become carers. This again makes an ‘information strategy’ of great importance since it is unlikely that many of
the ‘new carers’ will be aware of their rights, or of the support available. Likewise, many of those ceasing to be carers may be in need of information concerning their options – eg employment, training and benefits advice.

THE SPECIFIC DUTY

4.6 Section 1 Carers Equal Opportunities Act 2004 places a duty on social services authorities to inform carers of their right to a carer’s assessment. This duty arises when the social services department is either:

a) carrying out a community care or Children’s Act assessment of a disabled person or is:

b) contemplating undertaking such an assessment.

4.7 It is a proactive obligation. The social services department must first decide whether the carer provides or intends to provide a substantial amount of care on a regular basis, and if it is thought that the carer does, then the social services department must inform him or her of the right to request an assessment. It is then up to the carer to decide whether or not to ask to be assessed.

4.8 Local authorities should aim to make the information available in ‘minority languages and a variety of formats including easy to read, Braille or audio tapes’ as well as seeking ‘other ways of providing information and advice that are sensitive to language and cultural needs may also need to be developed’.

4.9 There is no ‘duty to inform’ if the carer has recently been informed of his/her rights in another context (for instance a carer’s assessment has recently been undertaken or has had a shortened carer’s assessment has been undertaken as part of a hospital discharge of the person for whom they care – see para 7.27 below).

4.10 In addition to the statutory duty under section 1 of the 2004 Act, separate guidance requires social workers not only ‘to inform any carer who appears to be eligible [for a carer’s assessment] of their right to request an assessment’ but also ‘to ensure that the carer has been made aware of this right the assessor should give the carer a copy of the Department of Health’s leaflet How to get help in looking after someone – A carer’s guide to a carer’s assessment’.

THE EXTENT OF THE OBLIGATION TO ‘INFORM’ CARERS

4.11 Given the complexities of the law, the nature and extent of the information that social services departments are required to provide, is wide ranging.

4.12 Technically carers in such a situation have the right to be informed of their right to make two separate requests.

1. The first is the right to have an assessment of their ‘ability to provide and continue to provide care’ (ie whether their caring responsibilities are sustainable). This duty stems from section 1 Carers (Recognition and Services) Act 1995.

2. The second concerns their right to an assessment of their need for services under section 2 Carers and Disabled Children Act 2000.

4.13 In order to decide whether or not to exercise either or both of these options, the social services department will have to explain to the carer what these distinct assessments each entail and what benefits could flow from such
a process. This is a not inconsiderable task. It may, for instance, require an explanation of the difference between the two assessments: that one is aimed at ensuring that the carer’s needs are met (generally by the provision of community care services or Children’s Act services to the disabled person) – so that the caring role does not become unsustainable, whereas the other considers the services that could be provided to the carer alone. The carer will also need to be informed that in both cases, consideration will be given to his or her work, education, training and leisure aspirations.

4.14 In order to consider these aspirations the assessor will need to know what facilities exist and as to how they can be accessed – including the support that may be available from the local authority and other sectors. As the Combined Policy Guidance under the 2000 and 2004 Acts states (at para 28):

*[the assessment should] include a discussion with the carer about possible alternative care services to help enable them to take up opportunities to participate in these activities, as well as signposting carers to information and support services, for example Job Centre Plus or local voluntary organisations who may be able to offer help and support.*

4.15 The obligation on social services departments is reinforced by guidance on the Community Care Assessment Directions 2004\(^{39}\) that:

*Local authorities should continue to ensure that up to date and appropriate information on the range of support, entitlements and assistance available for carers is accessible in a variety of formats. This information should be offered to all carers, irrespective of whether the carer receives an assessment.*

4.16 Section 1(2) Chronically Sick and Disabled Persons Act 1970 obliges social services to provide general information about the range of services available to disabled people (whether provided by that authority or by ‘any other authority or organisation’). Guidance on this duty\(^{40}\) emphasised that its purpose was to ensure that ‘those who might benefit by help, and their families, should know what help is available to them and this is to be secured both by general publicity and by personal explanations.’

4.17 Follow up guidance also stressed the importance of information provision\(^{41}\) stating that:

1.3 *It is the responsibility of the practitioner to ensure that this published information reaches potential users and carers who are considering seeking assistance. The availability of such material should help practitioners in their task but will also mean that they will be more open to public challenge on the quality of service they provide.*

4.18 Most recently, the general duty upon ‘social services with their partners in housing and health’ to inform has been strengthened by the ‘Better Care, Higher Standards’ policy guidance\(^{42}\). This includes a requirement to have an information strategy that draws on:

the views expressed by users and carers to improve the accessibility of information. This would include making available accessible and user-friendly written information, including local BCHS charters. It should also include using and working with information/advice points such as libraries, Citizens’ Advice Bureaux, local voluntary agencies and community groups; considering the use of electronic media, including terminals at publicly accessible points and times, and the use of the Internet.
The practice guidance to the 2004 Act advises that a carers information strategy should (amongst other things):

- Ensure practitioners and carers have access to up-to-date information on local resources for supporting carers in education, training, employment and leisure.
- Ensure carers are offered appropriate support for the cared for person so that they can have the piece of mind to pursue their own interests
- Assess whether carers need funding for fees and transport when accessing education and training
- Offer assessments at flexible times to accommodate those in employment
- Produce an A-Z of Carers Services so that assessors have good sources of up to date information to enable them to support carers to access opportunities in training, education, leisure and employment
- Ensure assessors are aware of local and national sources of funding for carers’ services
- Ensure that other public bodies are also equipped with signposting information

THE SETTING AND FORMAT OF THE ASSESSMENT

PRIVATE MEETING

Guidance under both the 1995 and 2000 Acts have emphasised the importance of carers having the opportunity to have their assessments in private – ie away from the disabled person, if the carer so chooses. The guidance states that ‘the assessment should listen to what [carers] are saying and offer an opportunity for private discussion in which carers can candidly express their views’.

ADVOCACY / SUPPORT

Social services should ensure that carers are aware that they can have a friend or advocate present at their assessment. Commonly this may take the form of a Carers Support Worker from a carers centre attending to provide practical or merely moral support. It may however range from a family friend to a specialist advocate.

THE ACTUAL ASSESSMENT PROCESS

Although both the 1995 and the 2000 Act contain provisions enabling ‘directions’ to be issued by the Secretary of State / Welsh Assembly concerning the format of carers’ assessments, these powers have not as yet been used. The policy guidance accompanying the 1995 Act gives limited and general advice on the form such assessments should take (at paras 21-25), whereas slightly more detail is provided in the practice guidance including:

9.1 The assessment is not a test for the carer. It should not be prescriptive but recognise the carer’s knowledge and expertise. The assessment should listen to what they are saying and offer an opportunity for private discussion in which carers can candidly express their views … .
4.23 Guidance under the 2000 Act provides significantly more assistance in detailing the key attributes and approach of a carer’s assessment. The practice guidance, for instance, stresses that an ‘assessment is not a process for its own sake’ and should ‘not be a bureaucratic process based on ticking boxes’.

4.24 Not infrequently social services departments have handed carers a questionnaire which they have then been asked to complete themselves. This process is acceptable, provided (1) the carer is agreeable and (2) provided the local authority appreciates that this is not an assessment – merely a preliminary stage; and (3) provided the questionnaire is not so daunting that it has the effect of deterring carers from progressing further. As the guidance explains ‘self-assessment forms can help [social services] prepare for assessment ... best practice suggests that they cannot replace face-to-face assessment’. This means that carers should always be informed – not only that they have the right to a face-to-face meeting for their assessment (in private) but that this is the ‘norm’.

4.25 Specific guidance exists in both England and Wales concerning the assessment process. It emphasises that assessments should ‘focus on outcomes the carer would want to see help them in their caring roles and maintain their health and well-being’.

4.26 ‘Focussing on outcomes’ means that the social services department should have criteria that look to the future rather than the past – should be proactive rather than reactive. It means that a carer should not have to wait until there is a crisis before being offered assistance. Instead the approach should be to provide timely assistance (even if the immediate situation is not dire) if it enables a significant future problem to be avoided. In addition criteria should look to see what benefits could be achieved for any particular intervention. Accordingly an approach that ‘focuses on outcomes’ might sanction support for a carer at time when there is no immediate risk of a breakdown in care arrangements, but which would nevertheless have the potential to yield very substantial benefits in the future, for instance a well timed break that might enable a carer to access a new support network or opportunities.

THE CARER’S ASSESSMENT – KEY ISSUES

4.27 As noted above, people who provide (or intend to provide) ‘a substantial amount of care on a regular basis’ are entitled to a carer’s assessment. The law requires that assessments address two distinct questions.

1. The sustainability of the caring relationship
   The assessment must assess the carer’s ‘ability to provide and to continue to provide care’ for the person s/he cares for.

2. The work, education and leisure needs of the carer
   The assessment must specifically consider whether the carer
   (a) works or wishes to work; and
   (b) is undertaking, or wishes to undertake, education, training or any leisure activity.

SUSTAINABILITY

4.28 The 1995 Act requires an assessment of the carer’s ‘ability to provide and to continue to
provide care’. As noted above (see para 3.22 above) the practice guidance issued under the 2000 Act advised that⁵⁸:

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?

4.29 The English practice guidance to the 2000 Act suggests that in determining what is ‘sustainable’ four crucial dimensions of the carers’ experience should be considered⁵⁹ namely:

• autonomy,
• health and safety,
• managing daily routines and
• involvement.

4.30 These four domains derive from guidance issued to social services departments concerning the assessment of disabled people, namely the Fair Access to Care Services Guidance on Eligibility Criteria for Adult Social Care⁶⁰. The following section considers each of these domains in detail.

AUTONOMY / CHOICE

4.31 Coercion and compulsion have no place in the language that describes caring relationships. Whilst parents have responsibilities towards their children and spouses are liable to maintain each other – the law recognises that it is impossible to compel one individual to provide care for another. Good practice therefore dictates that carers should have the right to choose the nature and the extent of their caring responsibilities. Ultimately if a failure of care occurs – the state has a positive obligation to provide support.

4.32 The practice guidance to the 2000 Act⁶¹ explains that the concept of autonomy (in the context of caring relationships):

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

4.33 The practice guidance to the 1995 Act described the proposition in the following terms:

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

4.34 The choice available to carers should relate not only to the quantity of care they provide but also the quality or type of the caring roles they are prepared to assume. As the practice guidance to the 1995 Act⁶³ explains:

… it is important that care managers do not make assumptions about carers’ willingness to undertake the range of caring tasks, particularly those related to intimate personal care. This is highlighted in a discussion of spouse carers⁶⁴ which emphasises the difficulties faced by some husbands or wives when their ability to cope with changed behaviour or personality and/or tasks involving physical intimacy is taken for granted …
4.35 The practice guidance to the 2000 Act describes ‘an extensive loss of autonomy’ as a ‘critical risk’ for a carer – ie one that demands a response by the local authority. Such a situation would arise where the carer believed that s/he was essentially trapped, having no choice over their caring commitments – that no external support or respite was available. Such an extensive loss of autonomy would require a response from the social services department to the extent that it enabled the carer to recover a belief that s/he had ‘freedom to choose the nature of the tasks they will perform and how much time they will give to their caring role’.

HEALTH AND SAFETY

4.36 The practice guidance to the 2000 Act (para 69) describes the importance of assessments addressing the health and safety impacts on carers, in the following terms:

*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.*

4.37 There is substantial evidence to suggest that significant caring responsibilities can be harmful. A Princess Royal Trust for Carers’ report (2002) found that:

- 85% of carers had found that caring had an adverse impact on their health, with particularly high-risk groups including those who looked after people with serious or mental and physical illnesses, and long-term carers.

- caring had been to the detriment of the mental well-being of almost 90% of carers

- over 40% said their physical well-being had been affected by caring

4.38 A similar study by Carers UK research found that:

- 55% of carers reported they had significant health problems;

- 43% reported they had sought medical treatment for depression, stress or anxiety since becoming a carer (these problems were particularly apparent in young carers and carers looking after mentally ill people).

4.39 The practice guidance to the 2000 Act describes ‘the development of major health problems’ as a ‘critical risk’ for a carer – ie one that demands a response by the local authority. Such a situation would arise – not merely when a carer had been diagnosed a suffering from a serious illness, but also where a link had been established between an illness and the carers caring responsibilities (ie chronic stress and anxiety in a carer who already had high blood pressure or a history of stress related illnesses).

DUTY TO SAFEGUARD HEALTH OF CARERS

4.40 Local authorities have other healthcare duties to carers, in addition to their statutory responsibilities to take into account (during the assessment process) the impact that caring may have on a carer’s health and wellbeing. Most obviously there is the
general ‘duty of care’ under the common law – the duty to take reasonable steps to ensure that carers are not exposed to unreasonable risk of harm.

4.41 By way of example, a local authority may decide that it will not allow a staff member to manually handle a disabled person, because the task carries an unacceptably high risk of a back injury. If no alternative provision is made available by the local authority (e.g., moving equipment, two or more support workers to undertake the task, equipment to obviate the need for lifting etc.) then it may follow that the carer has to undertake this unsafe task.

4.42 Although carers are not ‘employees’ for the purposes of the ‘manual handling regulations’ and other health and safety at work legislation, they are persons to whom the authority owes a duty of care (respect for, and the support of, carers being at the heart of the community care reforms). If an authority fully conversant with the good practice and knowledge engendered by the regulations stands by and allows a carer to carry out tasks it believes to be unduly hazardous for its own employees, then it may well be liable in negligence for any injuries that result (unless, perhaps, it has taken steps to inform and/or train the carer in safe lifting techniques, etc).

4.44 Carers’ assessments should therefore address the extent to which caring responsibilities interfere with the ability of carers ‘to manage their daily routines’ as well as the extent to which they inhibit the freedom of carers ‘to maintain relationships, employment, interests and other commitments alongside their caring responsibilities’.

4.45 In this context the practice guidance to the 2000 Act states that a critical risk includes ‘an inability to look after one’s own domestic needs and other daily routines; a risk to employment or other responsibilities; a risk to significant social support systems or relationships’.

4.46 This categorisation of ‘critical’ is of enormous importance. It represents an explicit statement by the Government that a risk to a carer’s employment or a significant relationship is one that demands action from the statutory authorities. Thus if a carer is considering going part-time because of their caring responsibilities, or at risk of losing a significant relationship because of their caring responsibilities, then this is something that should result in a positive intervention by the social services department to ensure that support services are available to ensure that the caring responsibilities do not jeopardise the employment or the relationship.

MANAGING DAILY ROUTINES AND ‘INVOLVEMENT’

4.43 Carers should have the same life chances as anyone else. The mere fact they are providing care should not disentitle them to opportunities available to people who do not have caring responsibilities. To argue otherwise would be to suggest that it is legitimate to discriminate against carers in a way that would not be acceptable for any other group. If it is unacceptable to assert that disabled people should not expect to work or participate in education or expect to have meaningful personal relationships, then how could one possibly suggest that this is not also the case for carers?
EMPLOYMENT, TRAINING, EDUCATION AND LEISURE ACTIVITIES

4.47 The above categorisation of a risk to employment or other responsibilities as a ‘critical risk’ has been reinforced by further specific guidance and more recently by statute. In respect of the former, the practice guidance to the 2000 Act (at para 35) develops the theme in the following terms:

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 … .

4.48 Statutory reinforcement to this right has come via section 2 Carers (Equal Opportunities) Act 2004. This places a duty on social services departments when undertaking a carer’s assessment to specifically consider whether the carer:

(i) works or wishes to work;
(ii) is undertaking, or wishes to undertake, education, training or any leisure activity.

4.49 The effect of this provision in the 2004 Act is to radically redefine the way carers are considered by social services departments. The earlier Acts focused on sustaining the caring role – on carers’ ‘ability to provide and to continue to provide care’. However the 2004 Act directs social services towards an altogether different target – that of promoting inclusion – of ensuring that carers are not denied the life chances enjoyed by other sections of society. The Minister expressed this approach in the following terms:74

We want carers who wish to work to have the right to work. For those carers who wish to take part in education, we want that to be built in to the care plans that are put together for the person for whom they are caring. We want them to have the opportunity to engage in leisure activities, to the extent that I feel that it would be appropriate that if a carer wanted to take part in a physical fitness or aerobics class in the evening, the care plan should be adapted to ensure that the person could be cared for while the carer went out to engage in such activity. The fundamental life expectations that all members of the Committee would expect for ourselves and for our families are often denied to carers because of their responsibilities and duties.

4.50 Carers’ assessment procedures must therefore ensure that carers are encouraged to consider routes by which they can maintain or engage in employment, life-long learning, training and leisure activities. In order to address these questions social workers will need to be able to direct carers to appropriate information
sources on these subject areas – see para 4.4 above for local authority ‘carer information obligations’.

4.51 The importance of carers being encouraged into work (or to remain in work) and to participate in education, training and leisure activities – is central to the government’s social exclusion and health development strategies.

4.52 It is also possible that carers’ employment rights are protected by the European Union’s Equal Treatment Framework Directive 2000/78/EC – and this question is considered at para 4.68 & 4.69 below.

PROMOTING CARERS’ EMPLOYMENT

4.53 The Department of Health’s 2001 report Carers and Employment found that local authority carers’ assessments did not address carers’ employment aspirations – particularly when the person for whom they cared was being discharged from hospital. In this context, a House of Commons Research Paper on (what became) the Carers (Equal Opportunities) Act 200476 noted that in such cases ‘the assumption was often made that there was no choice but that the carer should give up work’. With the coming into force of the 2004 Act, this approach is no longer lawful.

4.54 Very significant numbers of carers are of working age – possibly 80%.77 Research suggests that 60% of carers providing substantial amounts of care have given up paid work to care and that of these 70% find themselves financially worse off as a result78. A number of research reports have found that carers repeatedly stress the value of being able to go out to work79 and that possibly 80% would return to work if they could.80 It appears, that caring is not only damaging to the health of many carers (see para 4.37 above) but that it can also be economically crippling, with research suggesting that carers lose an average of £9,000 pa by taking on significant caring responsibilities and having to reduce working hours81.

4.55 The right of carers to maintain employment includes all carers, not least parent carers. The rights of parent carers are considered in greater detail in section 10 below82.

EMERGENCY LEAVE EMPLOYMENT RIGHTS

4.56 Carers have limited rights to take (unpaid) time off work to care for a dependant. This right is found in section 57A(1) Employment Rights Act 199683 of which provides:

57A. – (1) An employee is entitled to be permitted by his employer to take a reasonable amount of time off during the employee’s working hours in order to take action which is necessary-

(a) to provide assistance on an occasion when a dependant falls ill, gives birth or is injured or assaulted

(b) to make arrangements for the provision of care for a dependant who is ill or injured,

(c) in consequence of the death of a dependant,

(d) because of the unexpected disruption or termination of arrangements for the care of a dependant, or

(e) to deal with an incident which involves a child of the employee and which occurs unexpectedly in a period during which an educational establishment which the child attends is responsible for him
‘Dependant’ is defined widely in relation to persons who live in the same household and there is a general obligation upon carers who take such time off work, to tell the employer the reason for the absence as soon as practicable and how long the absence is likely to last. In relation to the situations detailed in sub-sections (a) – (c) above, the event which requires the carer to take time off need not be ‘unexpected’. Any time off work claimed as a result of this statutory provision is to be taken as unpaid leave.

**FLEXIBLE WORKING RIGHTS**

4.58 Parents with children under 6, or disabled children under 18, who have worked for their employer for at least 26 weeks have the right to apply for flexible working arrangements. Employers have a statutory duty to consider such requests seriously, and will only be able to refuse when there is a clear business reason or where the employee has made an application for flexible working in the past 12 months. In order to exercise this right the employee needs to make the initial written application to the employer. An employee can request a change to the hours they work, a change to the times when they work, or to work from home. Since any changes will be permanent it is important to consider the future implications carefully. This may include any drop in salary, and the impact that any reduction in hours may have on state benefits such as Working Tax Credit.

4.59 The Work and Families Act 2006 extends the benefits of flexible working rights to cover other carers. Section 12 of the Act makes provision for the Secretary of State to issue regulations which will widen the scope of the existing law to include (amongst others) people who have caring responsibilities for adults. The regulatory changes are expected to come into force in April 2007.

4.60 Section 12 of the 2006 Act amends s80F Employment Rights Act 1996, which enables a ‘qualifying employee’ to apply to his or her employer for a change in the terms and conditions of employment. Once the changes have come into effect, a carer who has worked for his or her employer continuously for 26 weeks will be able to request (for instance) a change in the hours they work or the times when they are required to work or to work from home (whether for all or part of the week).

4.61 The procedure for requesting flexible working rights will be governed by detailed regulations. These will oblige the employee to prepare a carefully thought-out application. The employer is then required to follow a set procedure to ensure the request is considered seriously: a refusal is only permitted where there is a recognised business ground for doing so. In November 2006 the Government published its proposals for the new regulatory framework with intention of publishing the regulations in December 2006.

4.62 On the 9th November 2006 the Department of Trade and Industry announced its decision on the definition of ‘carer’ for the purposes of the 2006 Act. It has decided that the definition of “carer” should include an employee who is or expects to be caring for an adult who:

(i) is married to, or the partner or civil partner of the employee; or

(ii) is a relative of the employee; or

(iii) falls into neither category (i) nor (ii), but lives at the same address as the employee.

4.63 Relative is to be defined as including parents, grandparents, adopters, guardians, and immediate relatives, namely sons, daughters, brothers, sisters, uncles, aunts as well as in-
laws and step-relatives of these immediate relatives. The definition will be contained in Regulations which will be published in early 2007. The Government has decided not to require in addition a level of care that has to be provided by such a carer, in order for them to have the permissive right (to request flexible working rights). In its view ‘defining a level of care would be extremely complex’; would be ‘unlikely to make matters any clearer’ and might deter some people from applying for flexible working if they felt that the definition did not cover their exact circumstances.

**PROMOTING CARERS’ INVOLVEMENT IN EDUCATION, TRAINING AND LEISURE ACTIVITIES**

4.64 Even if the carer is not seeking to maintain employment, the law requires that the carer’s assessment must actively encourage consideration of the possibility of undertaking education, training or leisure activities.

4.65 The importance of promoting participation in education and training has special resonance, with the Government’s social exclusion and full employment strategies. For many carers, the role is not a prolonged activity; indeed the research suggests that every year approximately 2 million adults become carers and approximately the same number cease to be carers. In order that they have the opportunity to regain full employment without being prejudiced by any gap due to caring, it is necessary that their caring responsibilities do not jeopardise their access to education and training opportunities.

4.66 To properly consider whether a carer wishes to undertake education, training or leisure activities (as required by section 2 of the 2004 Act), a local authority will need to ensure that those carrying out the assessment are aware of the education, training or leisure opportunities that may be available. This in turn requires a local authority strategy that ensures that assessors are trained in respect of this function and have access to a database or advice unit where relevant education, training or leisure information is readily available (see in this context para 4.19 above). Since social services authorities are also education authorities and frequently have significant leisure responsibilities – this calls for cross cutting initiatives to promote carers’ access to these services. This might for instance take the form of educational courses being run at times convenient to carers, with a central point for accessing respite support and possibly a policy decision taken on reducing course fees for or admission charges for carers (and so on).

4.67 In this context, the practice guidance to the 2004 Act notes that ‘many carers are on low incomes and carers may need support with costs for transport or college fees’ this does not however mean that the social services budget should necessarily be used to fund such a subsidy – as the combined policy guidance notes (at para 24):

> Not all the costs of offering wider, more flexible packages of support for carers fall within social services departments’ budgets. Other services, including education, housing, leisure facilities, libraries, and transport, can all provide a valuable contribution to the wider well-being of carers.

**CARERS’ RIGHTS UNDER THE EU EQUAL TREATMENT FRAMEWORK DIRECTIVE 2000/78/EC**

4.68 The Equal Treatment Directive is part of UK law and since 2006 makes unlawful direct or
indirect discrimination on grounds of (amongst other things) disability\textsuperscript{96}. In many respects the provision reinforces the existing requirements of the Disability Discrimination Act 1995. However in one respect, it may go further. It is arguable that the Directive makes it unlawful to discriminate against a person on the ground of disability – even if the person is not disabled – provided the reason for the differential treatment is a disability related reason.

4.69 In Coleman v Law (2006)\textsuperscript{97} the Miss Coleman claims that she was discriminated against by her employers (who she left) on the ground of the disability of her son, for whom she is the primary carer. It is her argument that this contravenes the Directive since it amounts to discrimination on grounds of disability. In July 2006 the case was referred to the European Court of Justice for a ruling as to whether the Directive protects employees who though they are not themselves disabled are treated less favourably or harassed on the ground of their association with a person who is disabled. If the Court advises that the Directive does cover carers in such a situation this will amount to a radical strengthening of their rights in this field.

**ELIGIBILITY CRITERIA AND CARERS’ ASSESSMENTS**

4.70 The Practice Guidance to the 2000 Act (para 70) requires social services departments to grade the ‘extent of risk to the sustainability of the caring role’ into one of four categories – namely ‘critical, substantial, moderate and low’. The grading system is a formal determination of:

\[
\text{the degree to which a carer's ability to sustain that role is compromised or threatened either in the present or in the foreseeable future by the absence of appropriate support.}
\]

4.71 Although the grading system is modelled on that which regulates disabled people’s assessments (see para 6.4 below) the consequences of a categorisation are different. If a disabled person’s is assessed as having a ‘critical’ need, then this means that the local authority is under a duty to make services available to meet that need. However a categorisation of critical in relation to the caring relationship does not mean that the local authority is under a duty to make services available to the carer – since there is no duty under the 2000 Act to provide services (merely a ‘power’).

4.72 However, as a matter of public law, the categorising of a risk to the sustainability of a caring role as ‘critical’ brings with it an obligation by the authority to take steps to ensure that support is made available to ensure that this state of affairs did not continue (or come to pass). Although in such a situation the local authority is not obliged to provide the carer with services it is obliged to act. It has the choice therefore of providing the necessary support either to the carer by way of a service under the 2000 Act or by way of additional support to the disabled person by provision of a community care service. The bottom line however, is that the identification of a critical risk in a Carers Act assessment triggers a local authority obligation to make an appropriate response to address this risk.

4.73 As noted above, the four domains of carers’ need (including ‘critical need’) are aligned with those that apply when disabled people are being assessed under the community care legislation. Noting this common approach, the Department of Health’s ‘Practitioner’s Guide to Carers’ Assessments under the
CRITICAL

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

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

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

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.
Carers and Disabled Children Act 2000 (at para 8) stresses that there can be ‘no place for artificial divides in the assessment process’ (ie between carers’ needs and those of disabled people).

4.74 The judgement in R (Hughes) v Liverpool City Council (2005) provides a clear example of this point. The case concerned a serious failure by the local authority to properly meet the needs of a profoundly disabled young man. So severe had been the local authority’s failure, that it was argued that his rights under article 8 of the European Convention on Human Rights had been violated (the right to respect for his private life). The judge concluded that no such violation had occurred, although this was only because of the extraordinary efforts made by his carer (his mother). In the judge’s opinion the burden imposed on her had been ‘very great, even intolerable’. In this case the judge severely censored the actions of the local authority and required it to take rapid steps to remedy its short comings. It seems clear that if the carer had made a separate complaint to the Local Government Ombudsman she would have been entitled to not inconsiderable recompense in her own right.

HUMAN RIGHTS

4.75 The Liverpool judgment (above) is evidence of the courts increasing willingness to articulate the experiences of carers in the language of fundamental human rights. In R (A & B, X & Y) v. East Sussex County Council (2003) Munby J stressed that disabled people’s rights under the European Convention on Human Rights had to be balanced against the corresponding rights of their carers (paid or unpaid). The impact of the Human Rights Act 1998 has also been considered in research commissioned by Carers UK.

4.76 It is not only in relation to the needs of disabled people (as above) that local authorities and NHS bodies must consider their Human Rights Act 1998 obligations: frequently the needs of the carer and disabled person are inextricably linked. In Miao v Home Department (2006) the Court of Appeal held that to deport a carer would interfere with the human rights of the person for whom he cared as well as the carer’s article 8 rights (right to family life). The Court in making this finding paid particular attention to a little known Immigration Service ‘Carers Policy’.

REFERENCES

25 Para 24-7; and para 4.3 of the Welsh guidance.
28 Department of Health (Social Services Inspectorate), Independence Matters, December 2003, para 5.25, p33, accessible at www.dh.gov.uk/assetRoot/04/06/95/17/04069517.pdf
29 Caring Relationships Over Time, Michael Hirst, SPRU, University of York, 2001
31 As the Combined Policy Guidance under the 2000 and 2004 Acts states at para 32 ‘many people who do not recognise themselves as a carer … To reach these and other hidden carers, local authorities may wish to consider working with local statutory and voluntary sector partners to develop strategies for better communication with ‘hidden’ carers about their right to request an assessment’.
32 ie under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. This obligation is achieved by amending section 1 of the 1995 Act (by inserting a new section 2B) and by amending section 6 of the 2000 Act (by inserting a new section 6A) accessible at
A statutory duty of this nature also exists in Scotland s11(2) Community Care (Scotland) Act 2002.

But has not as yet completed one (for instance because the disabled person is refusing to cooperate with the assessment).


Section 4(3) of the Community Care (Delayed Discharges etc.) Act 2003


Section 1 Carers (Recognition and Services) Act 1995

Section 2 Carers (Equal Opportunities) Act 2004.


This following two paragraphs do not appear in the Welsh
Guidance. The Welsh guidance on carers’ assessments does however expand upon the concept to a limited degree at para.2.4.4 accessible at www.wales.gov.uk/subicarersnew/content/practitionerseguidetocarersassessment.pdf The English Guidance *Fair Access to Care Services Guidance on Eligibility Criteria* at paragraph 40 adopts very similar wording to that which appears in the following two paragraphs accessible at www.dh.gov.uk/assetRoot/04/01/96/41/04019641.pdf. Likewise the Welsh Guidance *Creating a Unified and Fair System for Assessing and Managing Care* at paragraph 2.36 accessible at www.wales.gov.uk/subsocialpoliciesocialservices/content/managingcare.pdf


61 Practice guidance to the 2000 Act (para 69)

62 LAC (96)7 at para 9.8 WOC 16/96 and WHC (96)21 in Wales. For adult carers at paras 9-11 and for young carers at para 16.

63 LAC (96)7 at para 9.3 WOC 16/96 and WHC (96)21 in Wales. For adult carers at paras 9-11.


65 Practice guidance to the 2000 Act (para 70) – and see Table 1 below.


69 Practice guidance to the 2000 Act (para 70) – and see Table 1 below.

70 This will frequently include the manual handling risks posed to carers *R (Ireneschild) v Lambeth LBC* [2006] EWCA Civ 2354 (Admin.)


72 Practice guidance to the 2000 Act (para 69)

73 Practice guidance to the 2000 Act (para 70) – and see Table 1 below.

74 The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): Standing Committee C 10 March 2004 Column No. 7 accessible at www.publications.parliament.uk/pa/cm200304/cmstand/c/st040310/am/40310s02.htm

75 Carers and Employment: Report on Visits to Five Councils with Social Services Responsibilities, para 2.1, accessible at www.carers.gov.uk/visito5councils.pdf


77 Office of National Statistics, Census 2001

78 Carers National Association (now Carers UK) (2000) *Caring on the Breadline: The financial implications of caring*


80 *The True Cost of Caring, Caring Costs; Carers National Association*, 1996.

81 Caring Costs, (as above) 1996.

82 In the draft guidance – circulated for consultation – this statement was qualified by a clause to the effect that this would only be the case ‘provided it promoted and safeguarded the interests of the child’. After strong objection from a number of carers’ and disabled children’s support organisations this phrase was dropped from the final version of the guidance.

83 Inserted by s8 and Schedule 4 Part II of the Employment Relations Act 1999.

84 s57A (3) Employment Rights Act 1996

85 s57A (2) Employment Rights Act 1996


87 Under section 80F of Employment Rights Act 1996.

88 Accessible at www.dti.gov.uk/employment/workandfamilies/flexible-working/flexi-working-consresponse/page35184.html

89 *Draft Flexible Working: Regulations Summary of Responses and Government Response to the 2006 Consultation* DTI.

90 Section 2 Carers (Equal Opportunities) Act 2004
 Breaking the Cycle: Taking stock of progress and priorities for the future. A report by the Social Exclusion Unit Sept 2004, Office of the Deputy Prime Minister, London: para 1.61; and see also Full Employment – the next steps; Trades Union Congress (2004) which argues that in order to achieve full employment and economic growth the Government’s Spending Review 2004 should focus on getting into employment the two million people currently not in work but who want a job of which 500,000 are people with caring responsibilities

 Caring Relationships Over Time, Michael Hirst, SPRU, University of York, 2001

 Carers National Association (now Carers UK) (2000) Caring on the Breadline: The financial implications of caring

 SCIE practice guide to the Carers (Equal Opportunities) Act 2004 accessible at www.carers.gov.uk/whatsnew.htm


 C-303/06 The London Employment Tribunal Case Number: 2303745/2005

 [2005] EWHC 428 (Admin) 8 CCLR 243.


 [2006] EWCA Civ 75.

 Section 2 of Chapter 17 of the Home Office’s Immigration Directorate’s instructions; the policy is not restricted to applicants who apply from overseas. It applies to “persons here in a temporary capacity seeking leave to remain to care for a sick relative or friend”. The policy provides for admission to the UK as a visitor (i.e. not under the entry clearance route) for three months with a view to making care arrangements, and for subsequent extensions of permission.
5. Services to support carers

5.1 A carer’s assessment may have many outcomes. The mere presence and involvement of a sympathetic social worker will often provide considerable support and recognition: indeed it was because this aspect was so highly valued by carers that those promoting the 1995 Act chose to name it the Carers (Recognition and Services) Act. The assessment process should also be an opportunity for the assessor to advise the carer of the information and support services that are available – both generally and more specifically in relation to work, education, training and leisure activities (as noted above).

5.2 The legislative purpose of the assessment, however, is to provide information that enables the social services department to decide what additional services or support should be provided:

(a) to the disabled person; and
(b) to the carer.

5.3 If these services are provided to the disabled person, then they will be provided under the community care or Children Act legislation. However if the services are required by the carer – then they will be provided either via the Carers and Disabled Children Act 2000 or (if the carer is aged under 16) via the Children Act 1989.

COMMUNITY CARE SERVICES

5.4 The object of a carer’s assessment under the 1995 Act is to identify his or her ‘ability to provide and to continue to provide care’. Whilst the Act makes no provision for services for carers, the outcome of such a carer’s assessment will not infrequently be an increase in the community care services provided for the disabled person.

5.5 This is because the carer’s assessment, by focusing on the sustainability of the caring relationship, may identify areas where it is no longer sensible or safe for the carer to continue providing care – or where the carer is simply unwilling to continue. In such cases the care plan will need to be modified to ensure that the disabled person continues to receive the care that is needed – albeit that this care will be provided by someone else.

5.6 Thus, if a carer is no longer willing or able to provide help to the disabled person with (for example) bathing, the disabled person’s care plan will need to specify how this need is to be met in the future. Likewise if a carer is no longer able to remain with the disabled person (because s/he has obtained employment or simply needs to take a break) then the care plan will need to specify how the disabled person’s need for supervision/support at such times will be met in the future.
RESPITE / SHORT BREAK CARE

5.7 It follows from the above analysis, that respite care services are services provided to a disabled person which enable the carer to take a break from his or her caring responsibilities. In other words, respite care support is legally a community care service not a service provided under the Carers and Disabled Children Act 2000 (but see also para 5.19 below). This state of affairs has been explained by the Department of Health in a ‘Questions and Answers’ note that accompanied the enactment of the 2000 Act. It posed the question ‘are short term breaks (respite care) a service for carers or cared for people?’ and then answered this in the following terms:

People who care may be assessed as needing a break from their caring role. This need will be clearly recorded on their own assessment documentation.

The person they care for will then be assessed for the additional support that they will need to allow their usual carer to take a break. This need will be recorded on their assessment documentation. The additional service remains a community care service delivered to the cared for person, not a carer service under this Act.

5.8 Although respite care will be recorded as a service on the disabled person’s care plan (eg ‘a sitting service’), there is nothing wrong with the ‘break’ that the carer enjoys as a consequence being recorded as a ‘service to the carer’: ie the carer’s care plan recording that s/he has been given a 'break' (see also para 5.19 below).

5.9 Since respite care services are technically (ie as a matter of law) community care services rather than services provided under the Carers Acts, it follows that once a disabled person has been assessed as needing respite care, the local authority is legally obliged to provide services to meet this need. The disabled person will of course be liable to pay the local authority’s charges for the service.

5.10 ‘Respite care’ is not a phrase used by the law. In general terms, if a disabled person needs someone to sit with them, whilst their carer takes a break, the sitting service is a service provided under s 2(1)(a) Chronically Sick and Disabled Persons Act 1970 – which refers to ‘the provision of practical assistance’ in the home. Likewise if a disabled person needs to spend a short time in a care home whilst the carer takes a break, then legally this is the provision of ‘residential accommodation’ – either under s21 National Assistance Act 1948 if the disabled person is 18 or over, or under s17 Children Act 1989 if a child.

5.11 The importance of timely respite care/short break services has been repeatedly highlighted by research, guidance and case law. By way of example, guidance to the 1995 Act referred to research that suggested that ‘some of the most cost effective care packages were where carers continued to perform caring tasks but were given sufficient support and respite to enhance their well being and maintain their own health’.

WITHDRAWING / NOT PROVIDING RESPITE CARE

5.12 Respite care services are services provided to disabled people, to ensure that they are not at risk of harm when their carer takes a break or is otherwise unable to provide him or her with care. As with all disabled people’s services, once a local authority has decided that such a care need must be met, then it is under a duty to provide services to meet that
need. The courts and Ombudsman have repeatedly emphasised that a failure to provide such support will be unlawful. Thus in a 2000 case (concerning a placement in a residential care home the courts stated:\cite{109}:

\begin{quote}
Once a local authority determines that an individual’s needs call for a particular provision the local authority is obliged to make that provision. In particular having decided that an individual requires the provision of a permanent place in a nursing home … a local authority could not … refuse to make such a provision simply because it did not have the necessary resources.
\end{quote}

5.13 In relation to waiting lists, the court and Ombudsman have been similarly forceful. The Ombudsman in a complaint report concerning Essex\cite{110} has stated:

\begin{quote}
The Council believes it does not have to provide a care service or funding for care immediately it has decided that it is necessary to provide the service to meet a person’s assessed needs. It considers that it is acting correctly by having a waiting list on which the time a person may have to wait for resources to become available is indeterminate and depends to a significant extent on the needs and priority of other people on the waiting list and those who may come on to the list. That cannot, in my view, be correct.
\end{quote}

5.14 An Ombudsman’s complaint against North Yorkshire County Council\cite{111} illustrates the approach of the Court and Ombudsman. The complaint concerned a 17 year old person with multiple and profound mental and physical disabilities. Although primarily cared for by her parents she attended a special day school and for over 10 years went one weekend every month for respite care to an independent residential respite care centre – where she was delivered by the school bus on Friday afternoon and collected on Monday morning – providing the parent carers with a monthly break.

5.15 Because of a shortfall in its funding, the independent home advised the parents that it was no longer able to provide weekend respite care. The parents were devastated by this news. The council indicated that they would not provide any substitute weekend respite care and although the parents complained – the effect of this loss of service resulted in them both having nervous breakdowns and their marriage of 25 years ended.

5.16 The Ombudsman was extremely critical of the local authority’s failings: extracts from her lengthy report, include

\begin{quote}
The Council says that because it was not responsible for the closure of [the independent respite centre], it cannot be held responsible for the withdrawal of Marie’s provision. I do not accept this. It is the Council, not [the independent respite centre], which has statutory responsibility for providing for Marie’s needs. If [the independent respite centre] could not, for whatever reason, meet those needs, the Council had a duty to find, in the locality, somewhere else where Marie would feel equally settled and in which her parents would have confidence. …

I have noted too with disappointment that the Council did absolutely nothing to make [the parents] aware of the statutory provision for carers. There cannot be another family whose need will have been more pressing. The Council’s efforts at publicising the Carers (Recognition and Services) Act fall far short of what the Government has said it should do. …
\end{quote}
It is perhaps appropriate to mention at this point the comment of the Review Panel in dismissing part of [the parents complaint] on the ground that weekend respite was not necessary to meet Marie's needs but their wishes. This comment, combined with the Council's policy that carers must negotiate with service providers when their respite can be accommodated, does not, in my view, sit comfortably with government guidance. Government guidance says that services must be user driven, that users should not have to fit into what is available and that parents should be allowed to choose the pattern of use which suits them best. In a family coping against such odds and with another child to consider, I suspect their needs and their wishes are probably indistinguishable.

RESPIE CARE AND VOUCHER SCHEMES

5.17 Sections 3 and 7 Carers and Disabled Children Act 2000 provides for local authority social services departments to run short term break voucher schemes. Voucher schemes are designed to offer flexibility in the timing of carers' breaks and choice in the way services are delivered to disabled people for while their usual carer is taking a break.

5.18 Regulations made under s3 of the 2000 Act have come into effect in England (but not as yet in Wales) followed by Department of Health guidance ‘Carers and Disabled Children’s Act 2000 – Vouchers for short-term breaks – Policy and Practice Guidance’. The essential details of the English scheme being:

• All voucher schemes must now be in accordance with these regulations.
• Vouchers may be expressed in terms of money; or a period of time but a time voucher must specify the service for which the voucher may be redeemed; and may specify the supplier of services authorized by the local authority to supply that service.
• Community care time vouchers may be issued:
  – to a person cared for, or
  – a carer, provided the person cared for either consents to this or is unable to consent through lack of capacity
• Children Act vouchers, may be issued to a parent-carer.
• Money vouchers may only be issued in the case of a community care voucher to a person cared for, or in the case of Children Act vouchers to a parent-carer.
• Vouchers must not be issued to persons who are proscribed under the Direct Payment regulations.
• All vouchers must be redeemed within the financial year during which they are issued; a voucher is redeemed on the day on which the service that is secured against the value of the voucher is delivered.
• A voucher shall only be redeemable for services supplied by (a) the local authority that issued the voucher (the "issuing authority"); or (b) a relevant supplier of services.
• Where the voucher holder indicates s/he wants to use a supplier with whom the local authority does not have a contract the authority must enter into a contract with this supplier provided the preferred supplier agrees and complies with the authorities usual terms and conditions.
• If the service user ceases to be ordinarily resident in the issuing authority's area
without the full value of any vouchers held in relation to him being redeemed, any vouchers which remain unredeemed on the day on which that person ceases to be so ordinarily resident must be returned to the issuing authority.

- Where a voucher holder wishes the supplier to provide additional or more expensive services, this may occur if a third party agrees to pay to the supplier the difference between the cost which will be met by the voucher and the actual cost of the service supplied ["third party" means someone other than the service user, the parent-carer, or the issuing authority].

- A voucher must not be used to secure residential accommodation:
  
  (a) for a period in excess of 28 consecutive days; and
  
  (b) in any period of 12 months for periods which exceed 120 days in total.

**SHORT BREAKS & PERFORMANCE INDICATOR AUDITS**

5.19 Some confusion has arisen concerning the recording of respite / short breaks care for auditing purposes. Although as a matter of law the service given to the cared for person that enables their carer to have a ‘break’ is a community care service – for auditing purposes the ‘break’ itself may be recorded as a ‘service’ in its own right for the carer. This is indeed the approach adopted by the Commission for Social Care Inspection in England, which requires authorities to record the number of ‘breaks services’ that they have provided for carers.\(^{113}\)

**CARERS’ SERVICES**

5.20 Section 2 Carers and Disabled Children Act 2000 enables social services departments to provide services to carers following a carer’s assessment. The Act does not define what is a carer’s service other than to stipulate that a carer’s service can be anything that could ‘help the carer care for the person cared for’\(^{114}\).

5.21 In general a service to a carer under the 2000 Act cannot involve any intimate care of the person for whom they care. This question is considered separately at para 9.10 below.

5.22 The guidance accompanying the Carers Acts give examples of the type of services that could be provided to carers, including:

2000 Act practice guidance

- Trips (such as holidays or on special events);
- Driving lessons
- Travel assistance (including for instance help with taxi fares)
- Training
- Laundry
- Gardening
- Help with housework

Combined Policy Guidance under the 2000 & 2004 Acts

- driving lessons, moving and handling classes, a mobile phone, taxis to work to maximise the carer’s time, or a short holiday for the carer to enable them to have time to themselves [para 65]

2004 Act practice guidance

- A computer for a carer who could not access computer services from local library because he felt unable to leave the person he cared for.
- Repairs/Insurance costs for a car, where transport is crucial to the caring role.
- Entry phone with audio/video system where the carer lives in a two storey house and has mobility problems.
- £500 contribution to a flight for a Grandmother to come from another country and care for a woman with MS. Rural homecare could not deliver.

5.23 The range of services capable of being provided under section 2 Carers and Disabled Children Act 2000 is potentially vast, given that anything that promotes a carer’s sense of personal well-being is likely to help them ‘care for the person cared’. The reference in the guidance to ‘best value’ and the fact that there is no ‘duty’ to provide the services, means that in practice the provision of such services will depend upon the social services department being satisfied that they are a cost effective means of sustaining the caring relationship. Carers’ support services may include the provision of equipment – for example a mobile phone.

5.24 In relation to the provision of carers’ services, the practice guidance accompanying the 2000 Act\textsuperscript{115} states (amongst other things):

\textit{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.}

5.25 The Combined Policy Guidance under the 2000 and 2004 Acts emphasises this point (at para 18), stating ‘a carer may be best supported through being given help with routine domestic chores rather than through additional community care services to the person they care for’.

5.26 If the carer and disabled person are living in the same household, and housework is provided by the social services department, it will almost certainly be a disabled person’s service\textsuperscript{116} rather than a service provided to the carer under the Carers and Disabled Children Act 2000. Even though the above guidance requires social services to ‘review their positions’ in relation to home help and other low level services, it remains the case that social services tend to give such services low priority even if assessed as being needed by the disabled person – rather than the carer. This approach is unlawful and has attracted robust criticism from the Ombudsman, who has (for instance) held it to be maladministration for a council to have criteria which stipulate that no domestic assistance can be provided – unless accompanied by a need for personal care\textsuperscript{117}. Notwithstanding this finding, it remains the case that many local authorities continue to have such unlawful policies.

### DIRECT PAYMENTS

5.27 Section 5 of the Carers and Disabled Children Act 2000 enables social services departments to give carers direct payments instead of providing them with the service. Thus if a carer is assessed as needing a service such as driving lessons or relaxation therapy and the local authority decides that it will provide this support, the carer has the right to have the assistance provided as a direct payment – with which he or she then undertakes to purchase the service assessed as being required.
5.28 Guidance on the direct payments scheme has been issued in both England\textsuperscript{118} and Wales\textsuperscript{119} which provides detailed advice on such matters as the quantification of the amount to be paid and the situations when a local authority is under a duty to make such payments and the conditions that attach to such payments.

5.29 It should of course be appreciated that where a short break is provided – ie a sitting service – this is almost invariably (but see para 9.10 below) a service provided to the disabled person and so would be recorded on the disabled person’s care plan. If the disabled person wants a direct payment in lieu of the local authority providing this service, then this can only be done if the disabled person meets the direct payment requirements – eg is able to manage the payment alone or with assistance.

**POWER AND NOT A DUTY**

5.30 Section 2 of the 2000 Act gives social services departments a power, rather than a duty to provide support services for carers. This is in contrast to the law in relation to disabled people – which creates a duty to provide services in certain situations. However, the mere fact that the obligation is discretionary rather than mandatory in nature does not mean that it can be ignored. Where a statute gives a public body a discretion as to whether or not to do something, then it is unlawful for that body to have a blanket policy that it limits the scope of the discretion (for instance that it would not provide a carers service costing more than a specified amount or for a specific purpose – such as a holiday). Although public bodies are permitted to have ‘general guidelines’ as to how they will or will not use their discretionary powers they must never ‘fetter’ their discretion by having fixed or inflexible rules. In every case, the court or Ombudsman will need to be satisfied that the local authority considered whether or not to use its discretion and took into account the particular facts of the case. The courts will therefore consider that a policy is unlawful if “while in theory admitting exceptions [does not] in reality result in the proper consideration of each individual case on its merits”\textsuperscript{120}.

5.31 Carers’ services is being actively promoted by the Government in England and these are monitored along with Community Care Services benefiting carers through new Performance Indicators for Carers\textsuperscript{121}.

**REFERENCES**

103 These services can be provided either under the Community Care Legislation – generally where the disabled person is over 18 – section 46 National Health Service and Community Care Act 1990 accessible at www.legislation.hmso.gov.uk/acts/acts1990/Ukpga_19900019_en_4.htm#mdiv46 or under section 17 Children Act 1989 if the disabled person is under 18 accessible at www.legislation.hmso.gov.uk/acts/acts1989/Ukpga_19890041_en_4.htm#mdiv17

104 Services can be provided to carers aged 16 or over caring for someone 18 or over if under section 2 Carers and Disabled Children Act 2000 accessible at www.legislation.hmso.gov.uk/acts/acts2000/20000016.htm#2 or under section 17 Children Act 1989 if the disabled person is under 18 accessible at www.legislation.hmso.gov.uk/acts/acts1989/Ukpga_19890041_en_4.htm#mdiv17

105 Section 1(1) and s(2) Carers (Recognition and Services) Act 1995.

106 See for instance R (Hughes) v Liverpool City Council [2005] EWHC 428 (Admin) 8 CCLR 243 at para 33-34.

107 LAC (96)7 Practice Guidance para 9.3 (WOC 16/96 and WHC (96)21 in Wales): this advice is repeated in relation to adult carers at para’s 9-11 and for young carers at para 16.

108 D Challis et al, Care Management and Health Care of Older People (Canterbury 1995).

109 R v South Lanarkshire Council ex p MacGregor (2000) 4 CCLR...
188.

110 Complaint 00/B/00599 3rd September 2001; and see also


111 Complaint 01/C/03521 against North Yorkshire 19th
August 2002: [the names used are not the real names].

112 The Carers and Disabled Children (Vouchers) (England)
Regulations 2003 SI No. 1216.

113 CSCI PAF Guidance Book PAF C62 adopting the definition
that applied in the Carers Grant Guidance.


115 Para 80; the Welsh guidance contains no equivalent
statement.

116 Under s2(1)(a) Chronically Sick and Disabled Persons Act
1970 – ie ‘practical assistance in the home’.

117 Complaint No. 01/C/17519 against Salford CC 11.12.03

118 Direct Payments Guidance Community Care, Services for
Carers and Children’s Services (Direct Payments) Guidance
England 2003 accessible at
www.dh.gov.uk/assetRoot/04/06/92/62/04069262.pdf

119 Direct Payments Guidance Community Care, Services for
Carers and Children’s Services (Direct Payments) Guidance
Wales 2004 accessible at
www.wales.nhs.uk/documents/direct-payment-policy-e-
merge.pdf

120 R v Warwickshire County Council ex p Collymore [1995] ELR
217, at 224

121 These Performance Indicators can be accessed at the
Commissions for Social Care Inspection’s website
www.csci.org.uk/council_performance/paf/performance_indic-
ators.htm
COMMUNITY CARE ASSESSMENTS

6.1 If a carer is seeking assistance from the social services department, the first stage will in general be for the disabled person to have an assessment of his or her needs for social care support services. If the disabled person is over 18, this assessment will be known as a ‘Community Care Assessment’ whereas if the disabled person is under 18, the assessment will be known as a ‘Children Act Assessment’. These two procedures differ slightly – and are briefly described below. They can both, however, be broadly considered as having three key stages. The social worker must:

1. Gather all relevant information concerning the disabled person’s needs and requirements. This will include meeting with the disabled person and discussing his or her needs as well as contacting significant information sources such as family, carers, GP’s, housing etc.

2. Decide which of the various requirements identified during the first stage ‘call for the provision of services by the social services department’.

3. Construct a care plan to detail how these needs will be met by specified services.

6.2 When undertaking a community care assessment social services must follow detailed guidance issued by the Department of Health or Welsh Assembly. The main guidance in England is known as The Fair Access to Care Services (FACS) Guidance\(^{122}\), whereas the key guidance in Wales is known as the Unified and Fair System for Assessing and Managing Care’ (UFSAMC) 2002. These are very similar. In addition there is a plethora of other guidance – which is specific to certain user groups, for instance:

**Older People**
The Single Assessment Process Guidance\(^{123}\).

**Mental health service users**
The Care Programme Approach (1999)\(^{124}\).

**People with learning disabilities**
Valuing people guidance (2001)\(^{125}\).

6.3 When undertaking a Children Act assessment the local authority must follow detailed guidance issued by the Department of Health / Welsh Assembly. The main guidance in both countries is known as the Framework for the Assessment of Children in Need and their Families\(^{126}\).

6.4 An example of a community care assessment

Albert is 85 and lives with his wife who is his main carer. He has dementia which has now progressed to a stage that he is forgetful and without his wife’s help, he would neglect himself. He is physically frail and has fallen on a couple of occasions recently when trying to get upstairs to the toilet.
Stage 1

The social worker will try and get as much information about Albert’s wishes and requirements as is possible. This will include trying to discover what his interests and preferences are, in addition to key questions such as his need for basic physical care. At this stage, the views of his wife and other significant people in Albert’s life should be obtained even if these people do not want, or qualify, for a carer’s assessment. The views of the local health service must also be sought as well as enquiries made about the suitability of his housing and alternatives (for instance sheltered housing etc).

Stage 2

The second stage of an assessment requires the social worker to make a decision about which of the needs identified in the first stage, require the provision of services by the social services department. In order to ensure that people in the greatest need get priority for services, every social services department must publish its ‘eligibility criteria’. This is a scale which is divided into ‘critical’ ‘substantial’ ‘moderate’ and ‘low’ – with each category being described in some detail. The scale is set nationally, and derives from the FACS / UFSAMC Guidance (see para 6.2 above).

The social worker must then grade the person’s individual circumstances into one or more of these categories. Put very simply the social worker asks ‘what will happen if the authority does not respond to the identified need’ (eg help getting up, help with feeding and so on)?’. What will the consequence be for Albert? Will it be ‘critical’ ‘substantial’ ‘moderate’ or ‘low’? In doing this the local authority should initially ignore the help that Albert receives from his wife, his main carer.

Most local authorities have decided that they will provide services for people who are found to fall into the critical or substantial categories. A person will fall into such categories if, put simply, a failure to provide a service would result in them suffering significant harm.

If this test is applied to Albert’s needs (and his wife’s input ignored) and the question posed ‘what would happen if we did not have any help getting dressed in the morning; or help in the bathroom; or help in the preparation of food; or just keeping an eye on him to make sure he did not fall etc?’ The answer would almost certainly be that ‘he would be likely to suffer significant harm’. Accordingly the social services department will be under a duty to meet these needs.

It is at this stage that the authority should undertake a carer’s assessment of Albert’s wife to see if she is willing and/or able to continue to meet some or all of his care needs (see Section 4 above).

Stage 3

Having undertaken a carer’s assessment of the sustainability of his wife’s caring role and ascertained which of Albert’s various needs she is willing and able to meet, the social services department is then legally obliged to draw up a ‘care plan’ which describes the services that it will provide to meet his remaining care needs. The law also requires social services departments, to offer the disabled person ‘direct payments’ (if capable of managing these – alone or with assistance). This means that instead of the local authority providing (or arranging for the provision of) the services, the disabled person is given the cash equivalent with which to buy the services him/herself (see para 5.27 above).
An example of a Children Act assessment

Rupee is 8 years old and lives with her parents. She has significant learning disabilities and challenging behaviour associated with her autism. She has an older brother aged 11.

Rupee's social care needs will be assessed by the social services department under the Children Act procedures. The key guidance it must follow being 'the Framework for the Assessment of Children in Need and their Families' (see para 6.3 above)

Stage 1

The social worker will try and get as much information about Rupee's social care needs. This will include trying to discover what her interests and preferences are as well as looking into how her disabilities affect her family. The most recent FACS guidance (2002) was issued on 28th May 2002.

Stage 2

The second stage of an assessment requires the social worker to decide what services should be made available to Rupee and/or her family. It may be decided that the demands made by Rupee might need to be taken into account, for example, that on occasions she needs to be separated from her family – that they all have a break from each other – sometimes referred to as a short break or 'respite care'. This might mean that Rupee would stay elsewhere for a period of time with temporary foster parents (see para 6.3 above) or that someone comes to her home.

REFERENCES

122 The FACS guidance comprises policy guidance (which was published on 28 May 2002, under cover of a local authority circular, LAC(2002)13) and practice guidance. It is intended that the practice guidance be regularly updated — the most recent, at the time of writing (August 2003) was issued on 6th March 2003. Accessible at www.dh.gov.uk/assetRoot/04/01/97/34/04019734.pdf.


124 Effective Care Co-ordination in Mental Health Services – Modernising the Care Programme Approach and in Wales the Adult Mental Health Services in Wales: Equity, Empowerment, Effectiveness, Efficiency. A Strategy Document (2001).

www.wales.gov.uk/subichildren/content/framework-m/framework-m.pdf

127 Section 47(3) National Health Service and Community Care Act 1990.

128 Section 47(3) National Health Service and Community Care Act 1990.
7. The NHS’s Responsibilities

GENERAL CARER OBLIGATIONS

7.1 Neither the 1995 nor the 2000 Acts place any obligation on the NHS to address the support needs of carers. Given the extensive research concerning the caring related health problems that carers experience, this is a cause for considerable concern.

7.2 The guidance to the 1995 Act (LAC (96)7) did however advise (at para 29) that local authorities should ‘review with NHS commissioning agencies and NHS providers how they might best be involved in the carer’s assessment’, and then stating:

30. Primary care staff, including GPs and community nurses through their contact with users and carers, are in a good position to notice signs of stress, difficulty or rapidly deteriorating health particularly in carers. The provisions of the Act will help primary care staff to meet the medical and nursing needs of their patients who are carers. When making a referral for a user’s assessment they should be able to inform the carer that they may also have a right to request an assessment and will be well-placed to encourage patients whom they consider will benefit most to take up the opportunity. Social services departments should make sure that primary care staff have relevant information about social services criteria and know who to contact to make a referral. GPs nurses and other members of multi-disciplinary teams may be able to assist in an assessment of a carer’s ability to provide and continue to provide care.

7.3 Concern about the failure of the NHS to directly address the needs of carers prompted the Health Minister in 2003 to remind PCTs and other health providers of Government policy regarding the ‘critical role carers play’. The guidance she referred to stated:

Carers organisations have highlighted the limited inclusion of carers’ issues in health service planning as representative of a lack of recognition of their vital role. NHS organisations are reminded that in line with the 1999 National Carers Strategy (‘Caring for Carers’), they should be actively working in partnership with social services to consult, inform and support carers.

7.4 In June 2004 the Department of Health issued service delivery targets to NHS bodies, ‘The National Standards, Local Action Health and Social Care Standards and Planning Framework 2005/06–2007/08’. These require (amongst other things) that NHS staff treat patients, their relatives and carers with dignity and respect (C13) and take into account the views of patients, their carers and others when designing, planning, delivering and improving health care services (C17). In addition, as the Combined Policy Guidance under the 2000 and 2004 Acts makes clear
(para 34) it requires NHS organisations to cooperate with each other, with local authorities and with other organisations to promote, protect and improve the health of their community and narrow health inequalities.

7.5 In an attempt to give legislative force to these expressions of concern, the original draft of the Carers (Equal Opportunities) Bill (ie that prepared by Hywell Francis MP) contained two provisions. The first (clause 3) provided social services with a strong power to require positive cooperation by the NHS in relation to the provision of support for carers and the second (clause 5) required the NHS to promote the health and welfare of carers. Although the first provision is present in the final Act (albeit in less robust form – see para 7.12 below) the second is not. Hywel Francis MP agreed to withdraw clause 5 (the NHS duty to promote the health and welfare of carers) upon the Minister undertaking to issue directions requiring PCTs to include provision for carers in their local development plans (under s28 Health Act 1999)\textsuperscript{132}. Unfortunately the Government then changed its mind. The Minister and apologised for ‘having inadvertently misled Members’, and stated:

\textit{We can better deliver on the promise to ensure that PCTs will have to consult and take into account the health needs of carers through developmental support rather than through directing them through secondary legislation. I assure the House that although we will not proceed with the directions we will pursue alternatives}\textsuperscript{133}

7.7 It follows, that if a carers’ organisation (or an individual carer) considers that their local NHS is not taking positive action to promote the health and well-being of carers and / or failing to properly cooperate with other social care agencies, then complaint should be made to the Department of Health – given its Minister’s assurance that in such cases his department would intervene.

THE NHS DUTY TO COOPERATE

BACKGROUND

7.8 Research by Carers UK, \textit{Ignored and Invisible}\textsuperscript{135}, found that carers’ top priority was health and social services working together. Carers UK believes that better joint working between local social services departments, different local authority departments and other local public authorities, such as health bodies would deliver better and more cohesive support for carers. It would make it more likely that carers would be linked into other forms of support.

7.9 The House of Commons Research Paper\textsuperscript{136} that accompanied the Carers (Equal Opportunities) Bill stated that despite the good intentions of the \textit{National Strategy}\textsuperscript{137} it appeared that the advice concerning health joint working was not being applied and cited the Carers UK Report \textit{Missed Opportunities}\textsuperscript{138} which highlighted that
‘boundaries between organisations’ that were ‘hampering delivering support services which benefit carers’ and also pointed to other boundaries problems, commenting that ‘time after time carers spoke about the difficulties in arranging care and dealing with an array of agencies which were often disjointed and only able to meet part of their needs’.

THE GENERAL DUTY TO COOPERATE

7.10 There are a number of statutory duties on local authorities and the NHS to work together constructively, most importantly under s82 of the NHS Act 2006. Section 82 requires NHS bodies and local authorities ‘to co-operate with one another in order to secure and advance the health and welfare of the people of England and Wales’. Where a carer and or the disabled person suffer as a result of an inter-agency dispute, it is generally appropriate for complaints to be made against each authority – primarily on the basis that they have failed to ‘work together’ in breach of their duty under s82.

7.11 The Ombudsman has criticised health and social services authorities for failing to provide services whilst they squabbled over their respective obligations. One such complaint concerned the failure of a health authority and social services department to co-operate. Although the Ombudsman considered that the health authority’s involvement had been ‘reluctant, if not unhelpful’ she nevertheless found the social services authority guilty of maladministration. In her opinion, having accepted that a need existed, social services should have ‘grasped the nettle’ and secured the provision, before entering into protracted negotiations with the NHS on liability for the care costs.

THE DUTY TO COOPERATE UNDER THE 2004 ACT

7.12 Section 3 Carers (Equal Opportunities) Act 2004 reinforces the general duty under s82 of the 2006 Act. It provides:

- that a local authority may request another authority or health body to assist it in planning the provision of services to carers and persons being cared for. The bodies are other local authorities (with social services responsibilities), local education and housing authorities, and NHS bodies. These other bodies are required to give “due consideration” to such a request; and

- that where a local authority forms the view that a carer’s ability to provide care might be enhanced by the provision of services by another authority or health body it may request that other body to provide the service, to which request the other body must give due consideration.

7.13 In the light of this new statutory obligation the Combined Policy Guidance under the 2000 and 2004 Acts advises (at para 33) that social services and their local NHS partners:

develop a multi-agency carers strategy … [and to] … ensure that agreed protocols are in place for support from partner organisations in providing support to carers. This sort of process may also help to embed carers’ needs in other local strategies, for example, welfare to work, joint investment plans, hospital discharge plans and life-long learning strategies.

7.14 Research evidence produced by the Patients Association provides an example of the problems experienced by carers as a consequence of NHS failures in this respect – suggesting that approximately $2^{1/2}$ million people in the UK have had to take time off
work to arrange short-term post-hospital care for older relatives.

7.15 During the passage of the Bill the government described the expected impact of this provision:

I believe "due consideration" to mean that local authorities [and, it follows, the other bodies of whom a request may be made under the Bill] must give proper consideration to the request that has been made of them. They cannot dismiss it arbitrarily for reasons that they have set in a tablet of stone without due consideration of the merits of the individual case. They cannot have a blanket ban on considering all such requests, but must give proper and specific consideration to the request. They must take into account all relevant matters, including priorities and related issues. The key is that they must give specific consideration to the request. They must not simply take a blanket decision not to consider certain types of request.

The new Section is designed not to place onerous burdens on housing departments, other parts of local government or health bodies. It is, however, designed to ensure that public authorities properly consider requests for assistance made by social services authorities. That gives social services an opportunity to put their case, usually a strong one, about the benefits offered in individual circumstances.

7.16 In similar vein the Combined Policy Guidance under the 2000 and 2004 Acts advises (at para 36) that ‘due consideration means … an NHS organisation could not refuse to consider any request made to them in relation to the provision of lifting and handling support for carers. ... In demonstrating that due consideration has been given, it would be reasonable to expect public authorities to document the decision taken in relation to requests, along with the reasons for that decision’.

HOSPITAL DISCHARGE

GENERAL RIGHTS

7.17 All patients are owed a duty of care by both the NHS to take reasonable care of them. When it is thought that they are ready to be discharged from a hospital, this duty of care broadens: it is then shared with the social services department and encompasses carers who may be at risk if the discharge arrangements are badly handled.

7.18 ‘Safe discharge’ and ‘interagency cooperation’ are the key concepts for NHS and social care professionals. The discharge process must not put the patient or their carers at risk of harm and must not create a situation whereby the independence of the carer or the sustainability of their caring role is jeopardised.

7.19 Although patients have, in general, no right to remain in a hospital when their medical needs no longer make this necessary, this does not mean that their carers can be compelled to provide care to facilitate a discharge.

7.20 The relationship between the NHS and social services in the discharge process is shaped by central government guidance, and additionally (in England) by statute – the Community Care (Delayed Discharge etc.) Act 2003. The Act’s impact on carers is considered separately below (see para 7.27).

7.21 The key general guidance on discharge arrangements in England is known as ‘Discharge from hospital: pathway, process
and practice’ (2003) and in Wales as the Hospital Discharge Planning Guidance (2005). The English Guidance is more extensive and is cited in the subsequent paragraphs (being referred to as the ‘pathway’s guidance). The Welsh guidance echoes the English in many respects, stressing for instance (at para 24) the importance of ensuring that patients and their carers being fully engaged in all stages in the discharge process and being provided with written and verbal information in a range of formats appropriate to them (and so on).

PATIENT AND CARER INVOLVEMENT

7.22 The pathway’s guidance states that ‘the engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge’ (para 1.4). It further stresses the importance of patients and their carers being ‘kept fully informed by regular reviews and updates of the care plan’. This awareness is not restricted to older people: para 4.1 notes that young people may also be carers and ‘should be offered a carer’s assessment if they are under 16 years of age, when the adult receives a community care assessment’.

7.23 The pathway’s guidance acknowledges that carers have often considered themselves marginalised by discharge arrangements, particularly with patients being sent home too early (para 4.1) leaving their carers to cope with unacceptable caring situations. Working with carers is a responsibility of discharge coordinators – and it should not be seen merely as a social services function. If a patient refuses permission to allow their carer to be involved in decisions about their future care, carers should be informed of this and their right to an assessment reinforced. Carers should be given time to consider their options ‘in making what are often life changing decisions’ and they should be ‘informed about the support networks and services that may be available to them’ (para 4.3).

7.24 The pathway’s guidance makes the following important points (at para 4.3):

The need of the carer should be under constant review to take account of their personal health and social care needs as well as the caring role they are undertaking. The assessment and review process should consider the need for a short-term break from caring.

Patients may also have responsibilities such as being the parent of young children or as a carer of someone who has a disability and who is unable to live independently. It is important to identify whether an adult has dependent children and to ensure that arrangements are in place for their care during the period of admission. If the child is the carer of an adult with a chronic illness or disability, the child’s own needs for support must be addressed. It is vital that every effort is made to ensure that the family has sufficient services to ensure that children are not left with unacceptable caring responsibilities that affect their welfare, education or development. In addition, patients can also be carers, and it is important to ensure that if they are caring for someone that they have the right services upon discharge, to ensure that they can look after their own needs, as well as the person they are caring for.
INFORMATION /COMMUNICATION

7.25 In a number of investigations the NHS Ombudsman has been critical of hospitals who have failed to provide adequate information to patients and their carers, such that a right to challenge discharge from NHS funded care was lost. The Ombudsman has stressed that where the obligation to inform is a joint one with the social services, this does not excuse a failure by the hospital to provide the information (ie it cannot assume that social services will discharge its duty). The Ombudsman has also criticised as inadequate the provision of general brochures to patients and situations where staff provided patients and their carers with only limited advice on their possible options.

7.26 The pathway’s guidance stresses the importance of patients and their carers being ‘provided with information, both verbal and written, and in a range of media formats (to take into account any sensory or spoken language needs) on what to expect and their contribution to the process’. This should include details of arrangements, contact details and any relevant information regarding their future treatment and care (para 3.4).

COMMUNITY CARE (DELAYED DISCHARGE ETC.) ACT 2003

7.27 The Act is designed to encourage social services to speed up the discharge of patients who no longer require care in an acute hospital. It enables a hospital to serve on the relevant social services department an ‘assessment’ notice advising that a named patient is likely to be ready for discharge on a specified date. Within 3 days of receiving this notice the social services department must undertake a community care assessment of the patient’s needs and an assessment of any person caring for the patient who may be entitled to be assessed under the Carers Acts (ie a carer who will on discharge take on substantial and regular caring tasks for the patient. In relation to this assessment the guidance states:

Just as assessment for discharge need not be a full community care assessment, a carer’s assessment related to a patient discharge may be only part of a full assessment which continues after the patient is discharged. Where the carer will be undertaking lifting, or other tasks that need training to ensure that the carer or patient is not put at risk, staff should ensure that appropriate training is provided.

7.28 As with general ‘pathways’ guidance on hospital discharge, that which accompanies the delayed discharge scheme stresses the need for patients and their carers to be involved at each stage of the discharge process and to be informed of the proposed date of discharge at the same time or before social services.

7.29 In addition to providing full information to the patient / carer and undertaking a community care and a carer’s assessment, the hospital and social services must not pressurise them (by adopting tight timescales) to make a premature decision about future care placements. The guidance advises that they should be offered the option of postponing such a decision with the offer of an interim care package. However a refusal by the patient or carer of such a package has the effect of absolving social services from its liability to pay the NHS for a delayed discharge – because the delay is not solely attributable to a social services failure.
NHS CONTINUING CARE

7.30 Although in general the provision of social care services for disabled elderly and ill people, living in the community is the responsibility of social services authorities, in certain situations the duty to arrange these passes to the NHS. This situation occurs when a person’s needs for nursing and other care support are deemed to be above a level that can be provided by social services. Such persons are described as qualifying for ‘NHS Continuing Care’ support.

7.31 In the leading case on this question, R v. North and East Devon health authority ex p Coughlan, the Court of Appeal held that social services authorities had no responsibly for people in residential accommodation who were entitled to NHS Continuing Care support. Some social services authorities have incorrectly assumed that this means that they are no longer responsible for providing support for the carers of such persons. This assumption is understandable (given the complexity of the law in this field) but incorrect.

7.32 In the Coughlan case the Court of Appeal stated (in effect) that s21(8) National Assistance Act 1948 prohibited local authorities providing services under the 1948 Act for people who were entitled to NHS Continuing Care. Section 21(8) prohibits the provision of services under the 1948 Act if those services could be provided under the National Health Service Act 2006 or the National Health Service (Wales) Act 2006. It follows (in general) that the carer of an adult person who is in residential care funded by the NHS (ie a Ms Coughlan type person) would not be entitled to an assessment under either the 1995 or 2000 Carers Acts because these assessments are predicated on the carer caring for someone who might be entitled to community care services. That does not mean, of course, that the local authority cannot help them – it merely means that they are not obliged by statute to help them. As noted at para 9.6 the Local Government Ombudsman has been critical of councils who fail to provide support in such situations since other legislation – notably the NHS Acts of 2006 (see para 7.34 below) and s2 Local Government Act 2000 – empowers them to provide such support.

7.33 What is often overlooked, however, is that the Court of Appeal decision in Coughlan is limited to people in residential care. The exclusory effect of s21(8) of the 1948 Act only applies to people in residential accommodation and even if it has a more general application, its effect is merely to restrict services in such cases to those available under the NHS Acts of 2006. What is not generally appreciated, however, is that (a) under these Acts local authorities have duties to provide certain services including non-accommodation services to prevent people becoming ill; and (b) such services under these Acts are deemed to be ‘community care services’.

7.34 It follows that local authorities are empowered to provide community care services for people entitled to NHS Continuing Care support who are not in residential care and (in consequence) that their carers are entitled to assessments under the 1995 and 2000 Acts. It also follows that since carers are themselves of particular risk of becoming ill, local authorities are empowered to provide them (as services users in their own right) with services under the NHS Acts of 2006.
REFERENCES

129 HC Deb 6 May 2003 c663W
130 Department of Health, Chief Executive’s Bulletin, 28 March to 3 April 2003, para 8.
131 Accessible at www.dh.gov.uk/assetRoot/04/08/60/58/04086058.pdf
132 See the comments of the Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman) [Standing Committee C Wednesday 10 March 2004 Column Number: 14].
133 The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): House of Commons Hansard 14 May 2004 : Column 586.
134 The Parliamentary Under-Secretary of State, Department of Health (Lord Warner) stated “House of Lords Hansard 25 June 2004 Column 1493.
135 Ignored and Invisible, Carers UK, 2001
137 Accessible at www.carers.gov.uk/pdfs/Care.pdf
139 Complaint 96/C/3868 against Calderdale MBC
140 Being either ‘another local authority, an education authority, a housing authority or a Special Health Authority, a Local Health Board, a Primary Care Trust, an NHS Trust or NHS foundation trust’.
142 The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): House of Commons Hansard Standing Committee C Wednesday 10 March 2004 column 22.
143 Unless they are entitled to continuing health care support, detained under the MHA 1983 or have been in NHS accommodation for a prolonged period – such that it might be deemed their ‘home’ for the purposes of article 8 of the ECHR,
144 There is no present intention to bring it into force in Wales.
145 Department of health, accessible at: www.dh.gov.uk/assetRoot/04/11/65/25/04116525.pdf
147 Para 1.2 and at para 4.5.1 provides a detailed ‘carer’s checklist’ of relevant factors to be considered.

Carers England (2002). Hospital discharge practice briefing. London: Carers UK which reported that 43% of carers considered they were not given adequate support when the person returned home. See also Mather, J. et al. (2000). Carers 2000. London: Office of National Statistics.

149 Fifth Report for session 1995–96, Investigations of Complaints about Long-Term NHS Care, HMSO, complaint E.685/94-95
150 The above cited NHS Ombudsman’s Report, complaint E.672/94-95.
151 Maternity care, mental health care, palliative care, intermediate care and care provided for recuperation or rehabilitation are excluded from the definition of acute care.
153 See for example, ‘Frequently asked questions on reimbursement’ accessible at www.dh.gov.uk/assetRoot/04/07/19/26/04071926.pdf
154 ‘Frequently asked questions … ‘ as above Q. 28
155 ‘Frequently asked questions … ‘ as above Q. 29.
156 ‘Frequently asked questions … ‘ as above Q. 31.
159 As amended by the National Health Service (Consequential Provisions) Act 2006 Schedule 1 para 6.
160 Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004
161 As has been suggested by the High Court in R (T, D & B) v Haringey LBC (2005) [2005] EWHC 2235 (Admin) 21st October 2005.
162 Section 254 and Schedule 20 National Health Service Act 2006 and section 192 and Schedule 15 National Health Service (Wales) Act 2006.
163 Section 46(3) NHS and Community Care Act 1990.
8. Financial issues

CARERS’ WELFARE BENEFITS

8.1 This guide does not address carers’ benefit entitlement. Details of the range of benefits that may be available to carers can be obtained from Carers UK www.carersuk.org/Information/Financialhelp and the entitlement rules for carer’s allowance can be accessed at the Department for Work and Pensions website www.dwp.gov.uk/lifeevent/benefits/carers_allowance.asp

PAYING FOR SERVICES PROVIDED BY SOCIAL SERVICES DEPARTMENTS

8.2 Social services departments are permitted to charge disabled people for many of the community care services they receive and are entitled to charge carers for the services they receive under s2 Carers and Disabled Children Act 2000. Different rules exist depending upon whether the service consists of a place in a residential home or a service provided in the community. The rules also differ slightly in Wales.

8.3 Although this guide does not address the charging rules for disabled people’s services, two very important points of direct relevance to carers are:

SEPARATE TREATMENT OF CARERS & DISABLED PEOPLE’S INCOME

8.4 The charging rules for disabled peoples’ services stress that it is only the disabled person’s financial circumstances that can be taken into account. This means that even if the carer and disabled people are married, their financial circumstances should not be aggregated.

8.5 Thus the guidance on charging for residential care accommodation, the ‘Charging for Residential Accommodation Guide’ (CRAG) states (at para 4.001):

The LA has no power to assess a couple according to their joint resources. Each person entering residential care should be assessed according to their individual means, although liability of a married person to maintain their spouse [see para 8.8 below] should be considered in each case.

8.6 The same rules apply in relation to non-residential care services (for instance home help or day centre services). Thus the relevant guidance ‘Fairer Charging Policies for Home Care and other non-residential Social Services’ states that:

Users may be charged only for services provided to them and carers only for services provided to them under the Carers and Disabled Children Act 2000. Councils may not decide that a carer is the service...
recipient, and therefore subject to a charge, purely on the grounds that a user is exempt from charges or has an assessable income less than that of the carer.\(^{167}\)

8.7 The importance of not aggregating the financial resources of carers and disabled people in any charging assessment is further stressed by the Combined Policy Guidance under the 2000 and 2004 Acts (at para 62) which states:

*Carers cannot be charged for community care services provided to the people they care for (including the community care services provided to enable carers to take a break from caring) unless those services are provided as the result of a carer’s assessment under the 2000 Act.*

This means that (apart from the most unusual of situations – see para 9.12 below) carers cannot be charged for respite care services (see para 5.7 above) – or indeed another care service provided to the disabled person.

**LIABLE RELATIVE RULES**

8.8 If the carer and disabled person are married, then if at the conclusion of the assessment process the local authority provide support for a resident in circumstances where it believes that the resources of his or her spouse are such that s/he ought to make a contribution, then the authority can invoke the ‘liable relative’ rules under s42 National Assistance Act 1948. Guidance on the liable relative rules is given in the CRAG guidance at para 11.005.

**TREATMENT OF PROPERTY WHEN A DISABLED PERSON ENTERS A CARE HOME**

8.9 Chapter 7 of the CRAG guidance deals with the question of when the value of a disabled person’s home should be taken into account, for the purposes of residential home charging. The general rule is that the capital value of a property or former home is taken into account in full (less 10 per cent for disposal costs) unless one of the following disregards apply:

i) the value of a resident’s home is disregarded for the first 12 weeks of a permanent admission to residential care.

ii) The value of a dwelling normally occupied by a resident as his or her home should be ignored if his or her stay in a residential care or nursing home is temporary.

iii) Where the resident no longer occupies a dwelling as his or her home, its value should be disregarded where it is occupied in whole or in part by:

- the resident’s partner or former partner\(^{168}\) (except where the resident is estranged or divorced from the former partner – unless a lone parent); or

- a relative\(^{169}\) of the resident or member of his or her family (i.e., another person for whom the resident is treated as responsible) who:
  - is aged 60 or over, or
  - is aged under 16 and is a child whom the resident is liable to maintain, or
  - is incapacitated\(^{170}\).

iv) Where the resident has acquired property which s/he intends eventually to occupy as
his or her home, the value should be disregarded for up to 26 weeks from the date the resident first takes steps to take up occupation, or such longer period as is considered reasonable.

v) Local authorities have an overall discretion to disregard the capital value of premises, not covered by the above exceptions, in which a third party continues to live. Paragraph 7.007 of CRAG suggests that:

LA’s will have to balance the use of this discretion with the need to ensure that residents with assets are not maintained at public expense. It may be reasonable, for example, to disregard a dwelling’s value where it is the sole residence of someone who has given up their own home in order to care for the resident, or someone who is an elderly companion of the resident particularly if they have given up their own home.

8.10 It follows that the value of a home will be ignored if the disabled person enters a care home permanently and the carer who remains is either his or her spouse or common law partner. If however this is not the case, the statutory disregard only applies if the carer is a relative (including an ‘in-law’) and is either 60, or a child or step child of the disabled person, or ‘incapacitated’. If this is not the case, then the carer should ask the local authority to exercise its discretion to ignore the value of the home – and many local authorities currently do this – especially if the carer has provided care for a number of years.

CARERS GRANT

8.11 As part of the 1999 National Strategy for Carers, the Government announced the creation of a Special Grant for Carers which was to be paid to local authorities ‘for the enhancement of services to allow carers to take a break from caring’. A similar initiative followed in Wales. In England the underlying purpose of the Grant has been explained as to:

- further develop innovative and high quality carers’ services in response to local needs.
- develop pragmatic, outcome focused approaches to the carer’s assessment, integrated with the development of the Single Assessment Process by April 2004 and promotion of joint working with health services.
- focus on the needs of carers, which is often the most effective way to prevent loss of independence. In line with Fair Access to Care Services, local authorities should ensure no assumptions are made that caring roles can be sustained without assessment and the possibility of support for the carer. For further information Quality Standards for Local Carer Support Services was published by the Department of Health in February 2000.
- provide breaks for carers who provide substantial and regular care to a ‘relevant adult’ who lives at home and has been assessed under the NHS and Community Care Act 1990.
- provide breaks services for disabled children and their families under part 3 of the Children Act 1989.
- support children and young people (under 18) who are carers in having a break from caring; or
- fund voluntary organisations to provide breaks directly on the basis of their own assessments. Level of commissioning of
voluntary organisations should be determined by local need and reflect stakeholders views.

- fund administration relating to local carers strategies and consultation with carers.
- in line with good practice, councils are encouraged to agree a plan with stakeholders to ensure the grant is spent on locally agreed priorities.

8.12 Research suggests that the grant has been effective in promoting flexible breaks for carers. In England (2005/06) it amounts to £185 million. Since April 2004 the grant has ceased to be ring fenced in England albeit that local authorities will continue to be monitored by the Commission for Social Care and Inspection on the extent to which they are providing such respite care services. Commenting on this change the Minister (Stephen Ladyman) stated “[although] the carers grant … ring fence will be removed for next year … it is still a targeted grant. A very explicit memo explains to councils what the carers grant is intended to do, and we will back that up with inspections of councils to ensure that carers are still being cared for.”

REFERENCES

164 Section 8 Carers and Disabled Children Act 2000.
165 The version of CRAG applying in England can be accessed at www.dh.gov.uk/assetRoot/04/10/72/94/04107294.pdf and that in Wales can be accessed at www.wales.gov.uk/subihealth/content/keypubs/pdf/crag-comp-e.pdf
166 The English Guidance can be accessed at www.dh.gov.uk/assetRoot/04/08/64/74/04086474.pdf and the Welsh at www.wales.gov.uk/subisocialpolicy/content/consultations/charging/guidance-e.doc
167 Para 81 of the English guidance and para 69 in Wales.
168 This need not therefore be a ‘spouse’. CRAG does not provide any clarification as to how ‘partner’ should be interpreted. It is possible that it may now be deemed to include a same sex partner – see Mendoza v. Ghaidan (2002) [2002] EWCA Civ 1533; [2002] 4 All ER 1162; [2003] 2 WLR 478.
169 ‘Relative’ is specified as including: parents, parents-in-law, sons, sons-in-law, daughters, daughters-in-law, step-parents, step-sons, step-daughters, brothers, sisters, grandparents, grandchildren, uncles, aunts, nephews, nieces and the spouse or unmarried partner of any except the last five (para 7.004). The relevant point here is that this is an inclusive definition rather than an exclusive one.
170 The meaning of ‘incapacitated’ is not defined by the Regulations, but CRAG suggests that it includes a person receiving (or whose incapacity is sufficient to that required to qualify for) one of the following ‘incapacity benefit, severe disablement allowance, disability living allowance, attendance allowance, constant attendance allowance, or an analogous benefit’. Again this is an inclusive rather than an exclusive definition (see para 7.005).
171 Regulations Sch 4 para 18.
172 www.carers.gov.uk/pdfs/Care.pdf
173 See www.wales.gov.uk/subicarersnew/information-e.htm
174 Carers Grant Guidance 2004 / 05, para 5, accessible at www.carers.gov.uk/carersgrant04_05.PDF
175 The Kings Fund second "analysis of local authority plans and progress reports to assess the effectiveness of the Carers Special Grant in promoting flexible breaks for carers" (2001)
176 See Determination of a Grant under s31 of the Local Government Act 2003 of the Carers Grant for 2005/2006 accessible at www.dh.gov.uk/assetRoot/04/10/41/41/04104141.pdf. In Wales the Grant amounted to £23m in 2004/05 – see www.wales.gov.uk/subicarersnew/content/2-years-grant-e.htm
177 This means that local authorities are free to use the grant money as they chose and are no longer compelled to use it to fund carer related support services: see ‘Carers Grant 2004/2005 Guidance’ accessible at www.carers.gov.uk/2004_05carers_grant_guidance.PDF
178 House of Commons Hansard – 6 Feb 2004 : Column 1063
GENERAL PRINCIPLES

9.1 The Circular that accompanies the Community Care Directions 2004, (LAC (2004)24)\textsuperscript{179} gives general advice as to appropriate local authority responses where there is (or may be) be conflict between a carer and the disabled person, including:

- There will be cases where the person whose care is being planned lacks the capacity to consent to the involvement of carers, or to the care plan itself. In these situations best practice suggests that the carers should be involved as much as possible, currently local authorities have a responsibility to make decisions in the best interests of the person being cared for (para 2.3).

- If disagreements occur between the person and their carer, these should be handled sensitively, safeguarding the best interests of the individual and the carer. In many cases it may be appropriate for a resolution to be sought through independent or statutory advocacy (para 2.4).

- If it is felt to be inappropriate to involve the carer local authorities should retain a written account of why it was felt to be inappropriate. This should show that the carer’s involvement has been actively considered and, if excluded from care planning, the reasons why. It is not enough to state that the reasons were considered, without recording those reasons (para 2.5).

WHERE A DISABLED PERSON REFUSES A COMMUNITY CARE ASSESSMENT

9.2 Under the Carers (Recognition and Services) Act 1995 carers did not have a right to a ‘free-standing’ assessment (unless of course they are entitled to a community care assessment in their own right, by virtue of being an elderly, ill or disabled person). Carers only qualified for a carer’s assessment when the person for whom they cared was ‘being’ assessed. The carer’s assessment had therefore to coincide with the disabled person’s assessment. The Policy Guidance under the 1995 Act (at para 8) confirmed that this would also arise:

where a re-assessment of the service user is taking place, either as part of a review or because of a change in circumstances of either the user or carer arising for example, from a deterioration in the health of the user or a change in the carer’s ability to continue to provide care.

9.3 The requirement that the carer’s assessment coincide with a disabled person’s community care assessment caused some problem in practice – not least when a social worker was
confronted by a disabled person who was refusing to take part in an assessment. To overcome this difficulty s1 Carers and Disabled Children Act 2000 provides for a free standing right to a carer's assessment for carers (aged 16 or over) who care for a disabled adult. All that is required in such cases is that:

- the carer provides or intends to provide a substantial amount of care on a regular basis for a disabled person; and
- the carer requests the assessment; and
- the local authority ‘is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services’.

9.4 It has been suggested that an assessment under the 2000 Act can only occur if the disabled person meets their particular local authority’s eligibility criteria for services (see para 6.4 above). This is mistaken because the Act’s use of the word ‘may’ is deliberate: it means ‘has the power to’ – and not is ‘obliged to’.

9.5 It is unlawful for a local authority to have a policy or practice that denies carers support if the person cared for is not eligible for services. The plain meaning of the carers’ legislation is that a carer is eligible for support if the local authority ‘may’ provide support for a disabled person. The Act does not require a disabled person to be ‘eligible for services’ or ‘receiving services’. If Parliament wanted this to be the case, it would have said so. A few authorities have tried to argue that carers can only get support if the disabled person meets their ‘eligibility criteria’ for services – but this again is untenable. Not least because the eligibility bands [see para 6.4 (stage 2) above] are only guidelines – local authorities must have regard to them but to stick slavishly to them would be to fetter their duty. It follows that even if a disabled person's needs fall into a band for which the local authority does not generally provide services; it still has the power to (ie ‘may’) provide services for that person.

9.6 In general local authorities should assess carers who approach them requesting such assistance: they should accept carers’ account of their difficulties and not seek to rely on such abstruse arguments. They should not lose sight of their power to provide such assistance – even if there is no statutory duty and that in many such cases good practice will dictate that such an assessment be undertaken. As noted above (see para 3.27) the Local Ombudsman has been highly critical of a local authority that refused to undertake a carer’s assessment in such a situation.

WHERE A DISABLED PERSON REFUSES COMMUNITY CARE SERVICES

GENERAL GOOD PRACTICE

9.7 Not infrequently a disabled person will be refusing to accept services which would be of great benefit to the carer – for instance respite care (such as a sitting service or a short term placement in a care home – designed to give the carer a break). Frequently these can only be resolved by skilled and sustained social work. The courts have repeatedly held that social services departments cannot take a simple refusal (by a disabled person) of help at face value. They should continue to try and engage with the person.

9.8 The obligations on a local authority in such a situation are well illustrated by a 2004 Local Ombudsman report. In this case a carer was
enduring very considerable mental anguish because his autistic brother was continually getting into difficulties and seeking his help. Because of the brother’s autism, he was unable to form relationships and rejected an offer by the social services department to undertake a community care assessment. In the Ombudsman’s report she observed (at para 133):

I accept of course that the Council cannot force services upon an unwilling person. However, the Council took Mr K Hill’s refusals of some services or failure to persist with others at face value, instead of questioning whether he was in fact making an informed decision to refuse service or considering the implications for his brother. It is understandable that Mr K Hill might prefer his brother to continue to provide care rather than to accept more help from strangers, but the Council could not reasonably rely on Mr W Hill to continue providing the same direct input to his brother’s care, especially when he had explained his own difficult situation to them. They needed to find a way to work with both brothers on this issue. It is clear from the more successful interaction with Mr K Hill of the community nurse, the psychologist, and the worker from the voluntary caring organisation who became involved later, that it is possible to structure interaction with Mr K Hill in such a way as not to trigger his refusal of service through anxiety at having to cope with the person providing it. Why could not Council staff have done the same?

EXCLUSION FROM SERVICES

9.9 On occasions the disabled person may be excluded from services because of his or her behaviour. Often the behavioural difficulty will be a manifestation of the disabled person’s impairment – and in such cases the local authority’s obligations are to work with this problem and find a resolution. A failure to do this could result in enormous problems for the carer. The Local Ombudsman has criticised councils that have excluded disabled people from services in such cases. In a 2005 report the Ombudsman cited with approval the following reference in the White Paper Valuing People:

Excluding people with learning disabilities from services if they are found to be difficult to handle or present with challenging behaviour represents a major source of stress for carers, who may be left unsupported to cope with their son or daughter at home. This practice is unacceptable and families must not be left to cope unaided. No service should be withdrawn on these grounds without identifying alternative options and putting a suitable alternative service in place where possible. Decisions to exclude a person with learning disabilities from a service should always be referred to the Learning Disability Partnership Board, which will be responsible for the provision of alternative services in such cases …

FICTIONAL CARERS’ SERVICES UNDER S2(3) CARERS & DISABLED CHILDREN ACT 2000

9.10 Section 2(3) of the 2000 Act contains a provision designed to get around the problem of a disabled person who refuses services that would be of benefit to them and would also make a carer’s role less onerous. It states that a service, although provided to the carer -

(a) may take the form of a service delivered to the person cared for if it is one which, if provided to him instead of to
the carer, could fall within community care services and they both agree it is to be so delivered; but

(b) if a service is delivered to the person cared for it may not, except in prescribed circumstances, include anything of an intimate nature.

9.11 This arrangement is explained by the English practice guidance to the 2000 Act\textsuperscript{184} by reference to the following example:

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 carer’s 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 carer’s service provided for the carer (Jim), delivered to the carer (Jim). Jim would again be the person financially assessed in relation to any charges.

9.12 Accordingly certain care services, that would otherwise be construed as community care services may be deemed to be services under the 2000 Act. Such services can only be delivered to the carer, if:

• they could be a community care service
• both the disabled person and the carer agree to them being provided to the carer; and
• the services are not of an intimate nature (except in prescribed circumstances)

9.13 In respect of these services the English policy guidance to the 2000 Act\textsuperscript{185} states:

Cared for people may not be forced to accept services they do not wish to receive. However, in some circumstances they may accept a level of contact with social services that helps the person who cares for them. A cared for person who has refused an assessment may agree to the delivery of a non-intimate sitting service provided as a carer’s service to give their usual carer a short break.

9.14 Regulations\textsuperscript{186} define the meaning of ‘intimate care’ – stipulating that a service is deemed to be of an ‘intimate’ nature if it involves physical
contact such as lifting, washing, grooming, feeding, dressing, bathing or toileting the person cared for’. Such service cannot be provided to the cared for person under s2(3) of the Act (i.e. where the cared for person is refusing the service him/herself and so it is ‘fictionally’ being provided to the carer) except in ‘prescribed circumstances’. The Regulations\(^\text{187}\) clarify the scope of ‘prescribed circumstances’ as where (essentially):

a) the person cared agrees to the intimate care; or

b) in an emergency (which is likely to cause the cared for person serious personal harm) either

i) the cared for person is unable to consent; or

ii) s/he does not consent but the intimate care is necessary to alleviate the imminent risk of serious personal harm.

REFERENCES

\(^{179}\) Accessible at www.dh.gov.uk/assetRoot/04/08/83/70/04088370.pdf

\(^{180}\) Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004 accessible at www.lgo.org.uk/socserv.htm


\(^{182}\) Complaint No 03/C/16371 against Stockton-on-Tees Borough Council 18 January 2005 paragraph 13.

\(^{183}\) Valuing People, paragraph 5.7 and see also Circular HSC 2001/016: LAC(2001)23 paragraph s 37 & 38.

\(^{184}\) Accessible at www.carers.gov.uk/pdfs/practiceguidecarersparents.pdf page 33.


\(^{186}\) Regulation 2(1) of the Carers (Services) and Direct Payments (Amendment) (England) Regulations 2001 SI No.
10. Young carers

10.1 Carers who are under the age of 18 are generally referred to as ‘young carers’.

10.2 The Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004 apply to all carers irrespective of their age. In addition to the benefit of a carer’s assessment under the 1995 Act young carers are often entitled, to services in their own right, under the Children Act 1989. In general however it will be more appropriate for a young carer to be assessed under the 1989 Act. In this respect the Combined Policy Guidance under the 2000 and 2004 Acts states (at para 10):

*Children (anyone aged under 18) who are carers should be routinely assessed under the Children Act 1989. As a matter of law they could be assessed under the 1995 Act but that would not be expected, nor would it be in line with the Children Act 1989 guidance. Nevertheless, whichever of these Acts they were assessed under, the new obligation to consider a young carer’s wish to work or undertake education, training or leisure would still apply… .*

10.3 Whilst the 1989 Act will be the general assessment route for young carers – this will not always be the case. The obligations under the 1995 Act specifically encompass the needs of young carers because it is recognised that some adult services have in the past, failed this group. The 1995 Act obliges adult services to ensure that children and young people looking after an adult are not left with unreasonable caring responsibilities in the first place (see also para 10.8 and 11.11 below).

**RIGHTS UNDER THE CARERS (RECOGNITION AND SERVICES) ACT 1995**

10.4 Young carers, if they are providing or intending to provide a substantial amount of care on a regular basis, are entitled to an assessment under the 1995 Act. Although this is primarily directed at establishing their ability to provide and continue to provide care (the continuation of which may not be appropriate – see below) it must now (as a result of the 2004 Act) additionally address not only their desire to work (for example if a 15 year old wanted to take up a paper round) but also whether they wish to undertake, education, training or any leisure activity.

**YOUNG CARERS AND THE CHILDREN ACT 1989**

10.5 There is no legislation which specifically refers to young carers. Guidance concerning young carers has, however, been issued by the Department of Health and Social Services Inspectorate (SSI). The SSI guidance adopts a definition of a ‘young carer’ as ‘a child or..."
young carers. Such duties as are owed to young carers by a social services authority are primarily contained in the Children Act 1989 as clarified by guidance issued by the Department of Health

10.6 For a child to benefit from help under the Children Act 1989, it is necessary for him/her to come within the definition of a ‘child in need’. Under s17(10) Children Act 1989 a child is ‘in need’ if:

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

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

c) he is disabled.

10.7 The policy guidance under the 1995 Act (at para 14) referred to, and adopted specific guidance SSI which stated that:

many young people carry out a level of caring responsibilities which prevents them from enjoying normal social opportunities and from achieving full school attendance. Many young carers with significant caring responsibilities should therefore be seen as children in need.

10.8 A key determinant therefore is whether the young carer’s caring responsibilities are ‘significant’. In this respect the Practice Guidance to the 1995 Act points out (at para 15.2) that young carers should not be expected to carry out ‘inappropriate’ levels of caring. It follows that when undertaking a Community Care Assessment of a disabled or ill parent, the local authority must ensure that support mechanisms are put in place to prevent a young carer undertaking unreasonable caring responsibilities – or indeed suffering in any other inappropriate way. Accordingly if a young carer was unable to get to school, because of his or her parent’s disability, then this transport need should be addressed in the parent’s community care assessment (see also para 11.11 below).

10.9 Section 17(1) Children Act 1989 places a general duty on social services authorities to safeguard and promote the welfare of children within their area who are ‘in need’, and empowers authorities to provide almost unlimited services towards this goal.

10.10 The Children Act 1989 assessment procedures and service provision arrangements for young carers are the same as for any other child in need. Section 17(1)(b) emphasises that a principal purpose for the provision of services to children in need is to promote the upbringing of such children by their families.

10.11 Whilst the aim of a carer’s assessment under the 1995 Act is to assess the ability of the carer to continue providing care, the guidance emphasises this is not so in relation to young carers. Here the emphasis should be on ensuring – so far as it is possible – that ‘the person cared for is receiving sufficient services so that a young person ... is not undertaking a regular and substantial load of caring responsibilities’

10.12 Section 17(3) Children Act enables local authorities to provide services not only to the ‘child in need’ but to anyone else ‘if it is
provided with a view to safeguarding and promoting the welfare of the child in need. Accordingly this could be to a sibling young carer (if the child in need is, for instance, a disabled child) even if that young carer is not considered to be a ‘child in need’ in his or her own right.

10.13 The most recent policy guidance concerning the assessment of young carers issued by the Department of Health and the Welsh Assembly, the Framework for the Assessment of Children in Need and their Families196 states (amongst other things):

Assessing the Needs of Young Carers

3.61 A group of children whose needs are increasingly more clearly recognised are young carers for example those who assume important caring responsibilities for parents and siblings. Some children care for parents who are disabled, physically or mentally ill, others for parents dependent on alcohol or involved in drug misuse. …

3.62 An assessment of family circumstances is essential. Young carers 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 similar levels of caring responsibilities as adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities. There may be differences of view between children and parents about appropriate levels of care. Such differences may be out in the open or concealed. The resolution of such tensions will require good quality joint work between adult and children’s social services as well as co-operation from schools and health care workers. This work should include direct work with the young carer to understand his or her perspective and opinions. The young person who is a primary carer of his or her parent or sibling may have a good understanding of the family’s functioning and needs which should be incorporated into the assessment.

3.63 Young carers can receive help from both local and health authorities. Where a child is providing a substantial amount of care on a regular basis for a parent, the child will be entitled to an assessment of their ability to care under section 1(1) of the Carers (Recognition and Services) Act 1995 and the local authority must take that assessment into account in deciding what community care services to provide for the parent. Many young carers are not aware that they can ask for such an assessment. In addition, consideration must be given as to whether a young carer is a child in need under the Children Act 1989. The central issue is whether a child’s welfare or development might suffer if support is not provided to the child or family. As part of the National Strategy for Carers197, local authorities should take steps to identify children with additional family burdens. Services should be provided to promote the health and development of young carers while not undermining the parent.

10.14 As a result of amendments made by the Children Act 2004198, any assessment of a young carer must, amongst other things,

(a) ascertain the child’s wishes and feelings regarding the provision of [such services as the local authority is proposing to make available]; and
(b) give due consideration (having regard to his age and understanding) to such wishes and feelings of the child as they have been able to ascertain.

REFERENCES

188 Para 10 Combined Policy Guidance under the 2000 and 2004 Acts.


190 Guidance letter 28.4.95; CI (95)12


193 Guidance letter CI (95)12 Annex A para 1.1.

194 See also para 2.4 of Volume 2 1 1991 Children Act 1989 Guidance ‘Family Support’ which emphasises that ‘the definition of “need” in the Act is deliberately wide to reinforce the emphasis on preventive support and services to families’.


198 S17(4A) Children Act 1989 [inserted by s53 Children Act 2004].
11. Parent carers

11.1 People with parental responsibility for a disabled child (ie a person aged under 18) are (if their caring role is substantial) entitled to an assessment under Carers (Recognition and Services) Act 1995 and s6 Carers and Disabled Children Act 2000. It is self-evident that most parent carers provide a ‘substantial amount of care on a regular basis’. Neither the 1995 nor the 2000 Acts includes a stipulation (found in social security law) that the care provided to the disabled child must (for instance) be ‘substantially in excess of the normal requirements of persons of his age’.

11.2 Parent carers have a right to a separate assessment under the 1995 Carers Act in addition to their needs being fully addressed in their child’s Children Act assessment. In general, however, this should not be necessary, provided the local authority fully addresses the parent’s employment, training, education, leisure and other needs. As the Combined Policy Guidance under the 2000 and 2004 Acts advises (at para 71):

... Following the passage of the 2004 Act, the assessment should take account of the parent’s ability to provide or continue to provide care for the child and consideration of whether they work, or undertake any education, training or leisure activity or wish to do so. This means that local authorities have a duty to ask carers about these activities and take their wishes into account when planning the care package.

11.3 If a local authority is failing to implement its duties to parent carers (for instance in order to enable them to remain in work / rejoin the work force and/or take part in leisure training or education activities) then parent carers may have to insist on having a separate assessment under the 1995 and 2000 Acts. The right to such a separate assessment was put beyond doubt in R (LH and MH) v Lambeth LBC (2006). In this case the social services assessment accepted that the son’s behaviour was having an adverse affect on his mother’s health, emotionally, mentally and physically: that she was ‘depressed and at the end of her tether, crying all the time and only just coping’. However the care plan for the son failed to explain how his mother’s needs would be addressed. The Court declared that the local authority was in breach of its assessment obligations under the Children Act 1989 (to the child) and under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 (for the mother).

11.4 Parent carers (like all other qualifying carers) now have the right to have their employment, training, education and leisure aspirations addressed. This is of considerable value, since some authorities have previously been resistant to the idea of providing...
services which would enable a parent carer to return to work or maintain employment. In any carer’s assessment reliance can be placed upon the Government view that all ‘carers who wish to work to have the right to work’ (see para 4.49 above). The English practice guidance to the 2000 Act identified the importance of providing such assistance, stating (at para 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 childcare 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.*

11.5 The draft version of the above extract – circulated for consultation – contained a proviso to the effect that this would only be the case ‘provided it promoted and safeguarded the interests of the child’. After strong objection from a number of carers’ and disabled children’s support organisations this phrase was dropped from the guidance.

11.6 The problems that parent carers experience in relation to maintaining employment are considerable, not only due to the substantial demands often made by a disabled child, over and above those made by a non-disabled child. The additional problem concerns the shortage of child care facilities able to care for disabled children. For example, many working parents can benefit from the existence of ‘after-school’ clubs to provide child care – whereas these clubs may not be able (or prepared) to care for disabled children with challenging or specialist needs.

11.7 In this context, the above cited guidance to the 2000 Act (see para 4.45 above) is of particular importance – namely that if a carer’s assessment identifies a risk to his or her employment, then this is to be recorded as a ‘critical’ risk – and one that requires positive intervention by social services to address this risk.

11.8 The policy guidance to the 2004 Act amplifies this point, stating:

*the assessment should take account of the parent’s ability to provide or continue to provide care for the child and consideration of whether they work, or undertake any education, training or leisure activity or wish to do so. This means that local authorities have a duty to ask carers about these activities and take their wishes into account when planning the care package. For example, the package may provide the possibility of freeing some leisure time for the carer and for other children in the family through a structured playtime with the disabled child, while social services provides services to run the house. The local authority must take assessments carried out under section 6 of the 2000 Act into account when deciding what services, if any, to provide under section 17 of the Children Act 1989.*

11.9 The Childcare Act 2006 requires English and Welsh Councils (sections 6 and 22) to secure, ‘so far as is reasonably practicable’ sufficient childcare to meet the requirements of parents in their area who require childcare in order to work or to undertake training or education to prepare for work. In relation to disabled children, the obligation extends to childcare facilities up to the 1st September after their 18th Birthday. In determining whether the provision of childcare is sufficient, councils must have regard to (amongst other things) the needs of parents for childcare eligible for
the childcare element of the Working Tax Credit, and for childcare that is suitable for disabled children.

11.10 The Act will be implemented gradually – with the duty to assess the adequacy of child care provision coming into force in April 2007 – but the duty to secure sufficient childcare will not come into force until April 2008 with detailed guidance expected in April 2007.

DISABLED PARENTS

11.11 A number of research reports have highlighted the problems experienced by parent carers who are themselves disabled people. Many encounter particular difficulties in their dealings with the statutory authorities, due to the way these agencies are configured. Not uncommonly the adult and children services will be unclear as to who should take the lead. For example, if a mother’s impairment is such that she is unable to arrange for her child to be transported to school – is this a child care or adult care responsibility? Recent research has emphasised that although the law can cause confusion in this area, if the legislation is used flexibly appropriate packages can be delivered. It also emphasised that the approach in such cases should be to:

‘think parent’ and view disabled parents in the same way as non-disabled parents: the vast majority want to parent their children well. They may require additional support to do this, including where mainstream sources of parenting and family support for non-disabled parents are inaccessible to disabled people.

11.12 Department of Health guidance stresses that the child care needs of disabled parents should be treated as an adult care services’ responsibility and in general addressed in the parent’s community care assessment: that ‘in the course of assessing an individual’s needs, councils should recognise that adults, who have parenting responsibilities for a child under 18 years, may require help with these responsibilities’ (para 9). This advice is amplified in further guidance in the following terms:

... If adult parents have care needs that affect their parenting abilities and possibly impact on the well-being of their children, then councils should consider their duties under the Children Act 1989 and the use of the “Framework for the Assessment of children in Need and their Families”. Even when there are children’s needs to be addressed, it is wholly possible that aspects of the parent’s needs should be dealt with separately under the appropriate adult assessment framework, and FACS. Often it will be a matter of professional judgement on how to proceed in such cases. In exercising that judgement, professionals should bear in mind that the provision of services that assist disabled parents who need support in bringing up their children is often the most effective means of promoting the welfare of the children. Even though children may be well-cared for in domestic situation, an adult parent’s well-being could be undermined, and problems exacerbated, if s/he is not able to fulfil the parenting roles s/he aspires to. For this reason, “parenting roles and responsibilities” fall into those elements of the eligibility framework ... dealing with family and other social roles and responsibilities.
REFERENCES

199 Section 1(2) was inserted to deal with the question of parent carers; s1(1) is only activated where an assessment under s47(1) NHS&CCA 1990 is carried out and such assessments are generally limited to persons over 18; this is not however always the case, eg, if the assessment concerns a child entitled to services under Sch 20 para3 NHS Act 2006 and Sch 15 NHS (Wales) Act 2006 (which are community care services under s46 of the 1990 Act).

200 s72(6) Social Security Contributions and Benefits Act 1992


202 Draft guidance/regs concerning Childcare Sufficiency Assessments
www.dfes.gov.uk/consultations/conDetails.cfm?consultationId=1413


204 Olsen, R. & Tyers, H op cite.


206 Q4.2 Fair Access to Care Services (2003) Practice Guidance accessible at www.dh.gov.uk/assetRoot/04/01/97/34/04019734.pdf (and see also Q.41). In Wales the relevant guidance is to be found at page 65 – 66 of the Unified and Fair System for Assessing and Managing Care 2002 guidance accessible at www.wales.gov.uk/subsocialpolicysocialservices/content/managingcare.pdf
12. Carers of mental health service users and people who have ‘long-term’ conditions

CARERS OF MENTAL HEALTH SERVICE USERS

12.1 People with mental health problems are entitled to a community care assessment, in common with other disabled people. In some cases, however, they are entitled to additional assistance, under what is known as the ‘CPA’ which stands for the ‘Care Programme Approach’: an assessment procedure that applies to all patients receiving care from the specialist psychiatric services – i.e. regardless of whether or not the patient has been detained under the Mental Health Act 1983.

12.2 Because of concern about the low rate of carers’ assessments within the mental health services the Department of Health’s 1999 National Service Framework for Mental Health included a specific standard (Standard 6) entitling all qualifying carers to certain specified rights, namely:

**Standard 6 – Caring about carers**

All individuals who provide regular and substantial care for a person on CPA should:

- have an assessment of their caring, physical and mental health needs,
- repeated on at least an annual basis
- have their own written care plan, which is given to them and implemented in discussion with them.

12.3 The rights under Standard 6 are in addition to the basic rights that all carers of people with a mental health problem are entitled to. Thus if the person cared for is not receiving care from the specialist psychiatric services, then his or her carer will be entitled to an assessment under the Carers Acts of 1995 and 2000 (if providing or intending to provide regular and substantial care).

12.4 The rationale behind Standard 6 is explained in the following terms:

Carers play a vital role in helping to look after service users of mental health services, particularly those with severe mental illness. Providing help, advice and services to carers can be one of the best ways of helping people with mental health problems. While caring can be rewarding, the strains and responsibilities of caring can also have an impact on carers’ own mental and physical health. These needs must be addressed by health and social services.

12.5 Standard 6 contains detailed guidance on what action should be taken to support the carer. It requires social services to draw up a care plan and agree it with the carer and at the same time to take into account his or her health needs. The plan should be in writing and reviewed at least annually and its contents should be communicated to the GP and primary care team. The carer’s care plan should include:
• information about the mental health needs of the person for whom they are caring, including information about medication and any side-effects which can be predicted, and services available to support them
• action to meet defined contingencies
• information on what to do and who to contact in a crisis
• what will be provided to meet their own mental and physical health needs, and how it will be provided
• action needed to secure advice on income, housing, educational and employment matters
• arrangements for short term breaks
• arrangements for social support, including access to carers’ support groups
• information about appeals or complaints procedures.

CARERS OF PEOPLE WITH ‘LONG-TERM’ CONDITIONS

12.6 The National Service Framework for Long-term Conditions (2005) sets out a number of ‘Quality Requirements’ for the care of those suffering from long-term neurological conditions and their carers. Long-term conditions are defined as including conditions such as epilepsy, multiple sclerosis, motor neurone disease, Parkinson’s disease, post-polio syndrome, cerebral palsy and acquired brain injury (however strokes are covered in the NSF for Older People).

12.7 Although the Quality Requirements are aspirational in nature (in that they are to be progressively implemented by 2015) they nevertheless give a clear indication of the quality of service that people with these conditions and their carers should expect from the NHS and social services. Quality requirement 10 concerns the appropriate support and services for carers, and contains the following table of ‘evidence based markers of good practice’.

1. Carers of people with long-term neurological conditions:
   • can choose the extent of their caring role and the kinds of care they provide;
   • are offered an integrated health and social care assessment at diagnosis and all future interactions, together with information that addresses their needs;
   • are offered a written care plan agreed with them and reviewed regularly;
   • have an allocated contact person.

2. Involving carers is part of the planning process so that:
   • all carers are treated as partners in care and helped to acquire appropriate skills to support them in their caring role including how to move and handle the cared-for person and how to use equipment to help in daily living;
   • carers are given the opportunity to work in partnership with specialist teams.

3. A range of flexible, responsive and appropriate services is provided for all carers which:
   • deals effectively with emergency situations;
   • can support highly dependent people at short notice;
   • provides appropriate support for children in the family;
   • provides carers with breaks across a range of settings;
is culturally appropriate (eg to the
needs of black and minority ethnic
communities).

4. Carers who need help to adjust to
changes especially of a cognitive or
behavioural kind have access to support
based (where appropriate) on a whole
family approach and delivered (where
necessary) on a condition specific basis
and in partnership with the voluntary
sector; and

- current service models are evaluated to
  inform future good practice.

5. Staff working with people with long-term
neurological conditions receive carer
awareness education and training which
involves carers in planning and delivery

REFERENCES

- Social Services Inspectorate. Still Building Bridges (The
- A National Service Framework for Mental Health: Modern
  accessible at
  www.dh.gov.uk/assetRoot/04/07/72/09/04077209.pdf: In
  Wales an equivalent NSF was published in 2002, Adult Mental
  Health Services: A National Service Framework for Wales
  accessible at
  www.wales.gov.uk/subihealth/content/keypubs/pdf/adult-
  mental-nsf-e.pdf
- A National Service Framework for Mental Health (as above)
  page 69
- A National Service Framework for Mental Health (as above)
  page 72
- Department of Health (March 2005) accessible at
  www.dh.gov.uk/assetRoot/04/10/53/69/04105369.pdf
CARERS’ COMPLAINTS

13.1 Where carers are dissatisfied with the treatment they have received from a local authority or the NHS they are entitled to complain: for instance, a carer dissatisfied with their carer’s assessment or with the failure to keep them properly informed about the discharge from hospital of the person for whom they care (see para 7.21 above).

REPRESENTATIVE COMPLAINTS BY CARERS

13.2 Frequently, however, the carer does not wish to complain about the treatment they have received – but about the poor service received by the person for whom they care. The question in such cases is whether the complaints procedures allow for a carer to make a complaint in a ‘representative’ capacity. As a general principle, carers are entitled to make such complaints, where the person for whom they care, either:

1. agrees that the carer do so on their behalf; or

2. lacks sufficient mental capacity to complain on their own behalf; or

3. does not wish to complain but in all the circumstances the complaint raises issues of such importance that the authority should nevertheless investigate.

13.3 The following commentary considers each of these categories separately. For the sake of brevity, in this section the person for whom the carer provides care is referred to as ‘the disabled person’.

1. WHERE THE DISABLED PERSON AGREES.

13.4 Where carers make a complaint with the agreement of the disabled person – then they do so as the disabled person’s agent and have the same rights as if they were making the complaint personally. In such cases the NHS or local authority will wish to have in writing (if possible) confirmation from the disabled person that the carer is acting with their agreement. Authorities will also be concerned to ensure that they do not share confidential information without the disabled person’s consent, and so will additionally seek written confirmation that s/he is content that the carer has the same right of access to information.

2. WHERE THE DISABLED PERSON LACKS MENTAL CAPACITY.

13.5 Where a carer makes a complaint concerning the disabled person’s care but the disabled person is so lacking in mental capacity that it cannot realistically be said that s/he has provided informed consent for the complaint to be made, then the local authority or NHS will have to decide whether the complaint...
can proceed. As a general principle, to make such a decision, it will have to consider various matters, including:

a) whether the carer has a sufficient interest in the patient’s welfare to bring the complaint and

b) whether s/he is a suitable person to act as representative.

13.6 In all but the most exceptional cases a carer will self evidently be someone with a sufficient interest to bring such a complaint. It follows that generally the only question to concern the authority is whether the carer is a ‘suitable person’. Given (i) the vulnerable position of people lacking mentally capacity and (ii) the potential for a conflict of interest, authorities should be very cautious about deciding that a carer is not suitable. Where however such a decision is reached, the authority must then go on to decide whether it should nevertheless investigate the substance of the complaint (even if it seeks to provide an alternative representative for the disabled person – see below).

13.7 To make a finding that a carer is not suitable to act as a representative, the authority would need to be able to point to specific facts that constitute convincing reasons for making such a finding. These could, for instance, be a well established history of making malicious and unfounded complaints allied to evidence that the outstanding complaint is almost certainly of a similar nature.

13.8 Where, unusually, an authority concludes that a carer is not suitable as a representative it will have to decide whether nevertheless the complaint raises concerns that ought to be investigated. In such a case, the principle of fairness requires that the authority ensure that the matters forming the substance of the complaint are properly investigated and evidence obtained from all relevant persons (which will always include the disabled person and almost invariably the carer).

3. WHERE THE DISABLED PERSON DOES NOT AGREE

13.9 A carer may wish to make a complaint about the treatment of a disabled person even though the disabled person indicates that s/he does not wish the complaint to proceed. In general, where the disabled person has the mental capacity to make an informed decision to this effect, then this will be an end of the matter – in so far as s/he is concerned. However in such situations the authority will have to then consider whether the substance of the allegations is such that (a) the carer has a right to complain in their own right (ie in relation to the impact that the matters has had upon them) and/or (b) whether the issues should be considered in any event since, if true, they would disclose a situation sufficiently serious as to warrant action by the authority. Such an approach was taken by the Local Government Ombudsman in a complaint made by someone who accepted that she was not acting in a representative capacity. The Ombudsman nevertheless held that it was important that her ‘complaints were still given full and proper consideration in a way which equated to the standard of service a complaint would have received under the council’s formal complaints procedure’.

CONFIDENTIALITY

13.10 In the ordinary course of events authorities will be required to accept complaints made by carers in a representative capacity. In those cases where the carer lacks the express ‘informed’ consent of the disabled person, the local authority or NHS will need to
exercise greater caution in relation to the sharing of information. The following extracts from the 2006 Draft Code to the Mental Capacity Act 2005 (paras 15.20 – 15.26) provide some assistance in relation to the extent of disclosure in such cases:

Health and social care professionals have always disclosed information about people who lack capacity to, for example, family carers and other relatives, when it is clearly in the interests of the person lacking capacity do so. ...

Under the Act, the need for professionals to consult people who know the person who lacks capacity when determining best interests, will further encourage them to share information to make the consultation meaningful. However, at the same time, a person disclosing information concerning a person lacking capacity must … balance the right to privacy of the person who lacks capacity against what is in his/her best interests and/or the public interest.

Information may also be disclosed where there is an overriding public interest. It can be difficult to judge when it is in the public interest to disclose information and each case must be considered on its merits.

It should also be noted that the public interest may require disclosure where this is needed to enable action to be taken, e.g. to prevent a person lacking capacity suffering physical or mental harm.

Whenever information is disclosed, the carer may be asked to give an undertaking that the information will be treated in confidence, it will not be disclosed to anyone else (unless there is a lawful basis for doing so) and that will not be kept for longer than necessary. In many cases, the need to keep the information will be transient, and in those cases, the carer should be able to reassure the information holder that s/he will not keep a permanent record of the information. If the carer does intend to keep a permanent record of a decision, s/he should make it clear for how long s/he needs to keep the information on which s/he has based the decision.

LOCAL AUTHORITY COMPLAINTS

13.11 The procedures for complaining about local authority social services are about to be reformed216 and the final details of the new scheme has yet to be published. At present however slightly different procedures apply to complaints made by carers of disabled children to those that apply to carers of adults. The current procedures are however similar and although a detailed consideration of them lies outside the scope of this Guide217, the following is a brief summary.

13.12 Social services departments must appoint an officer who is responsible for co-ordinating all aspects of the complaints procedures (often called a ‘Complaints Receiving Officer’). In practice social services complaints procedures have three distinct stages, namely:

1) the informal or problem-solving stage;
2) the formal or registration stage;
3) the review stage.

(1) THE INFORMAL OR PROBLEM-SOLVING STAGE (SOCIAL SERVICES)

13.13 The initial stage is where the local authority attempts to resolve the matter informally. The relevant guidance explains that:

normal good practice should sort out, to the user's satisfaction, the queries and grumbles which are part of a social work department’s
daily workload. Stage 1 then alerts the relevant worker, supervisor or manager to the fact that there is a more fundamental problem, as perceived by the user or her or his representative. It gives users the right to decide whether or not to pursue the issue and ensures that it is taken seriously and not dismissed by busy staff. The fact, however, that this stage is not ‘formal’ does not mean that it is ‘casual’.

13.14 Local authorities should provide complainants with a simple explanation as to how the complaints process works and the relevant timescales.

(2) THE FORMAL STAGE (SOCIAL SERVICES)

13.15 If ‘informal’ process fails to resolve the complaint speedily, then it moves to the formal stage. At the formal stage, complaints should be put in writing. The mere fact that a complaint has progressed to the formal stage does not absolve the authority from its duty to try and resolve the problem\(^2\)\(^{19}\). The authority must consider the written complaint and then formulate a response within 28 days. If it is not possible to comply with the 28-day period, the authority must (within that period) explain to the complainant why this is so, and state when the response will be given. In any event, the response must be forthcoming within three months.

13.16 Authorities may, if the need arises, appoint an independent person\(^2\)\(^{20}\) at this stage to oversee the investigation, and if the complaint concerns services under the Children Act 1989, they must appoint such a person\(^2\)\(^{21}\). On occasions the investigation may also need to call upon specialist outsiders.

13.17 At the conclusion of its investigation, the local authority must notify the complainant (and the carer if s/he made the complaint) in writing of the result of its investigation.

(3) THE REVIEW STAGE (SOCIAL SERVICES)

13.18 The disabled person or his/her carers may, if dissatisfied with the outcome of the formal stage, request that the complaint be referred to a panel for review. Panel hearings are in private and are conducted as informally as possible. The Panel must produce a report setting out its findings and making recommendations. Although it is up to the local authority to decide whether or not to accept these recommendations, the courts have emphasised that, in the absence of special factors, the recommendations should be followed.

NHS COMPLAINTS

13.19 The process for complaining about the NHS varies slightly between England and Wales – although on matters of substance the two schemes are little different. As with the social services procedures, there are various stages in the complaints process – albeit in the NHS scheme, there are only two.

13.20 The statutory scheme places responsibility on individual NHS bodies for the first ‘local resolution’ stage of the complaints procedure and in England for the Healthcare Commission (CHAI) for the second ‘independent review’ stage – whereas in Wales the second stage is the responsibility of an Independent Review Secretariat which is part of the Powys Local Health Board.

13.21 Guidance has been issued in both England and Wales on how the complaints process should operate.
STAGE 1

13.22 The guidance provides considerable detail as to the process for investigating complaints. For instance, it requires that every NHS body (including GP practices) must have a complaints manager who must acknowledge any complaint within two days of its receipt223 and must then investigate it within 20 working days224, unless this is not possible, in which case it is to be done ‘as soon as reasonably practicable’.

STAGE 2

13.23 If dissatisfied with the outcome of the stage 1 process the complainant can ask for an independent review, either from CHAI in England or the Independent Review Secretariat in Wales. The request must generally be made within two months in England (28 days in Wales)225 of the response. CHAI or the Independent Review Secretariat in Wales must acknowledge the request, and then decide what action to take – which might for instance include226:

(a) to take no further action (in which case the complainant must be advised of his/her right to complaint to the NHS Ombudsman); or

(b) to refer the complaint back to the NHS body with recommendations as to what action might be taken to resolve it; or

(c) to convene an independent panel to consider the complaint

OMBDUSMAN

13.24 Complainants in England who remain dissatisfied with the outcome of the complaints process may then refer their complaints to the Local Government Ombudsman or the Health Services Ombudsman (depending upon whether the complaint concerned social services or the NHS). In Wales there is now a combined Ombudsman who investigates all such matters. The various Ombudsmen have comprehensive web sites which give details of the procedures for contacting them227.

REFERENCES

212 These two criteria are specifically identified as the key criteria by the National Health Service (Complaints) Regulations 2004 SI No. 1768, reg 8.

213 In Wales the NHS Complaints guidance Complaints in the NHS: A Guide to handling complaints in Wales (2003) states at para’s 1.15 – 1.18 that the process is ‘designed to address patients’ and relatives’ complaints’ and that where relatives and friends make complaints on behalf of patients the patient should either give written permission (if the response might include any personal information) or where unable to do this the investigation should nevertheless proceed

214 Because the authority could be accused of making such a finding to fend off an otherwise valid complaint

215 Complaint No. 94/C/2959 against Nottingham City Council; 28 November 1994 and see also Complaint No 97/C/1614 against Bury MBC (1999).

216 The Health and Social Care (Community Health and Standards) Act 2003 provides the Secretary of State (the Assembly in Wales) with power to make regulations providing for a two-stage process for representations and complaints: s114 relates to adults and s116 to children (which inserts a new section, 26ZA, into the Children Act 1989).


218 Department of Health Right to Complain (1991) at para 4.3.


220 The Right to Complain para 4.12.


222 In England as Guidance to support implementation of the National Health Service (Complaints) Regulations 2004 and in Wales as Complaints in the NHS. A Guide to handling complaints in Wales: April 2003
Reg 11 NHS (Complaints) Regulations 2004 and page 3 of the Welsh guidance (see above).
Reg 13 NHS (Complaints) Regulations 2004 and page 9 of the Welsh guidance (see above).
Reg 14 NHS (Complaints) Regulations 2004 and page 6 of the Welsh guidance (see above).
Reg 16 NHS (Complaints) Regulations 2004 and page 58 of the Welsh guidance (see above).

In England the Local Government Ombudsman web site is at www.lgo.org.uk/; the Health Services Ombudsman is at www.ombudsman.org.uk/ and in Wales the Public Services Ombudsman for Wales is at www.ombudsman-wales.org.uk/