

CARERS UK
the voice of carers



CARERS AND THEIR RIGHTS

THE LAW RELATING TO CARERS

FIFTH EDITION 2012

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Contents

Section	Para
1. Introduction	
2. Definitions	3.
Social services obligations to Carers ~ overview	
The rights of all carers	3.11
Carers whose care is regular and substantial	3.14
Guidance	3.17
Personalisation & personal budgets	3.33
Law Reform	3.39
4. The Carers Assessment	
The duty to inform	4.7
The setting and format of the assessment	4.32
The Carers Assessment ~ key issues	4.39
Sustainability	4.40
Autonomy / choice	4.43
Health and Safety	4.50
Managing daily routines and 'involvement'	4.58
Employment, education & leisure activities	4.63
Eligibility Criteria and Carers Assessments	4.86
5. Services to support Carers	
Community Care Services	5.4
Respite / short break care	5.7
Carers services	5.28
6. The rights of disabled people ~ an overview	
7. The NHS's Responsibilities	
The NHS duty to cooperate	7.11
Hospital discharge	7.25
NHS Continuing Healthcare	7.40
8. Financial issues	
Paying for services provided by social services	8.2
Carers Grant	8.14
9. Carer / Service User conflict	
10. Young carers	

11. Parent Carers	
Disabled parents	11.14
12. Carers and specific categories of service users.	
Carers of mental health service users	12.1
Carers of people with 'long-term' conditions.	12.6
Carers and drug / alcohol misusers	12.8
Carers and immigration controls	12.11
13. Equality & Human Rights	
Carers and human rights	13.03
Carers and the Equality Act 2010	13.10
14. Complaining	
Confidentiality	14.9

Foreword

We are now entering a new phase for carers' rights with proposals under the draft Care and Support Bill for England which is shortly to be scrutinised by Parliament before it starts its parliamentary journey.

It will bring together all the elements contained so far in the Acts of Parliament dating back to 1986 contributed by myself and my fellow parliamentarians, Malcolm Wicks MP, Lord Pendry and Tom Clarke MP.

This new edition of Carers and their Rights is important in reminding us of what exists in law and will continue to exist until the draft Care and Support Bill becomes law. None of these rights will be weaker under any new legislation, and most stronger. In other words, the evidence set out here should act as a guide to the future when we may see implementation in 2015 or beyond.

This edition is dedicated to Malcolm Wicks MP who died in September 2012. Malcolm shares a special place in the history of the carers' movement, giving rights to carers for assessments of their own needs. He turned what was commonly an invisible role into one which was not only visible, but better valued and recognised. The beauty of Malcolm's Carers (Recognition and Services) Act 1995 was the fact that it covered all carers. This included carers supporting people with all different types of disabilities, frailty and chronic conditions and all groups of carers including parents of disabled children, young carers and adults caring for other adults. The fact that all three of these groups of carers have rights remains as important today as they were in 1995.

With an ageing population and more people living longer with disabilities in the community - a fact to be warmly celebrated - we must ensure that the family does not bear the heavy costs of caring. Our challenge now is to ensure that all public bodies and services implement the law and this guide to carers' rights will be an invaluable tool in helping to bring this about.

Dr Hywel Francis MP

Chair, Joint Committee on Human Rights and Vice-President of Carers UK

1. Introduction

- 1.1 The fifth edition of this guide outlines the principal rights of carers to support from health and social services authorities in England and Wales. As before, 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
- 1.2 In the period since the last edition there have been a number of statutory and case law developments which are noted in this text. The last year has also been marked by considerable law reform discussion and draft Bills have been published in both England and Wales (see para 3.39 below). In Wales, the publication of this edition coincides with the first tangible impacts of the Carers Strategies (Wales) Measure 2010 and this welcome development is considered further at para 4.26 below.
- 1.3 This edition also takes stock of the impact of the Equality Act 2010 (with its prohibition of 'associative discrimination') representing as it does a further milestone in the struggle by carers for equal treatment (considered at chapter 13 of this guide). The combination of this development, with the implementation of the Carers (Equal Opportunities) Act 2004 and the Work and Families Act 2006 means that a major cultural shift is taking place 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; people with a right to an ordinary life 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.
- 1.4 The depth of the social exclusion experienced by the UK's 6.4 million carers¹ stands in sharp contrast to these new 'inclusive' obligations. With the tightening of social care budgets, this disparity is becoming ever more obvious, as the former Commission for Social Care Inspection (CSCI) observed:²

¹ For data from the 2011 census, see Office for National Statistics (2012) Measuring national well-being: Households and families, 2012P.29 at http://www.ons.gov.uk/ons/dcp171766_259965.pdf

² Commission for Social Care Inspection (2006) *The state of social care in England 2005-06*. London: CSCI at para 7.106

there are major tensions for councils in their policies to support carers. They are charged with improving efficiency and targeting resources effectively and are consequently restricting eligibility to services. But at the same time they are looking to support carers, recognising the risk that without support many carers own health and well-being may suffer and they, too, will need help in their own right. The danger, as ever, is that carers are only seen as a 'resource' and some carers continue to be socially excluded and barred from the opportunities others would expect.

1.5 The difficulties experienced by carers can be highlighted by the following stark statistics:

- Carers lose an average of over £10,000 a year by taking on significant caring responsibilities.³
- Over half of all carers have a caring related health condition.⁴
- Due to financial difficulties, 23% of parent carers do without heating, 14% do without food and 73% do without leisure and days out.⁵
- Carers represent one of the most socially excluded groups of people – for whom social inclusion policies appear to have failed.⁶

1.6 The social and economic marginalisation of carers is not new – and their present problems are not a 'blip' caused by the current financial difficulties. Despite the political rhetoric, ever since the implementation of the 1993 community care reforms there has been a steady increase in the numbers of carers⁷ - reflecting the intervening neglect of 'social care'. Between 1992 and 2001 for example, there was a 28% reduction in the number of households receiving social care services.⁸ The research evidence establishes that this trend continues: the last 15 years have seen 'increasing care burdens for the family, friends and neighbours' (particularly of older people) accompanied by greater financial burdens for carers.⁹ Today,

³ Carers UK (2011) *The Cost of Caring*, and Carers UK (2007) *Out of Pocket, the financial impact of caring*.

⁴ The Health and Social Care Information Centre (2010) *Survey of Carers in Households 2009/10* at www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England_NS_Status_v1_0a.pdf and see also Carers UK, *Missed Opportunities: the impact of new rights for carers*, Carers UK June 2003.

⁵ Contact a Family, *Counting the Costs* (2010) and see also Carers UK (2008) *Carers in crisis* at www.carersuk.org/media/k2/attachments/Carers_in_Crisis.pdf

⁶ *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 6.17.

⁷ Patsios, D (2008) *Trends in the receipt of formal and informal care by older people* ERRC Bristol 2008.

⁸ Department of Health (2002) *Community Care Statistics 2001 Home care services for adults*, England London: DoH.

⁹ *Ibid.*

despite the significant rise in the population of older people, fewer of them are receiving support from local authorities – with the inevitable consequence that their carers are taking the strain.¹⁰ In the last year, there has been a 7% reduction in the number of disabled and older people receiving support from social services.¹¹

- 1.7 In the context of the current funding cut-backs (and the consequent transfer of caring responsibilities to carers) councils must not only take into account the impact that these will have on disabled and older people and their carers (see chapter 13) but must also pay full regard to the following advice contained in a 2007 Department of Health Report:

In considering costs, commissioners should take account of the hidden costs of failure to develop local services, such as the costs of handling crises and placement breakdowns They should also pay attention to the financial and other costs borne by carers and should avoid increasing the burden on carers by reducing levels of service. As one parent said “They never think about the costs of not doing it”.¹²

- 1.8 All, however, is not bleak. There was evidence that prior to the impact of the credit crisis the needs of carers were being given a higher priority by many authorities – evidenced in the fact that 60% of them have a ‘carer indicator’¹³ as a headline indicator in their local area agreements and in relation to the NHS, the 2008 Carers Strategy¹⁴ required that Primary Care Trusts ensure that their joint Strategic Needs Assessments (with their partner local authorities) contain a carer element, including a commitment to provide breaks for carers.

¹⁰ See, for example Commission for Social Care Inspection (CSCI) (2008) *The state of social care in England 2006-07*. Part one: The picture of social care: data and trends p18.

¹¹ Department of Health (2012) *Community Care Statistics: Social Services Activity, England 2010-11* London: DoH.

¹² Department of Health (2007) *Services or people with learning disabilities and challenging behaviour or mental health needs: Report of a Project Group (Chairman: Prof J L Mansell)* London Department of Health October 2007 at para 75.

¹³ Indicator NI 135 Carers receiving needs assessment or review and a specific carer’s service, or advice and information – see Department for Communities and Local Government (2007) *The New Performance Framework for Local Authorities & Local Authority Partnerships: Single Set of National Indicators* at www.communities.gov.uk/publications/localgovernment/nationalindicator

¹⁴ Department of Health (2008) *Carers at the heart of 21st-century families & communities* at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345 para 3.12

2. Definitions

Who is a carer?

- 2.1 There is no single definition of a 'carer' (often referred to as 'caregivers' in the USA). 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 commentators have used the term 'informal carer' to distinguish actual carers from paid 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.¹⁵ If a disabled person uses a community care direct payment to employ his or her carer, then this may (but may not) undermine that carer's entitlement to a Carers Assessment (see para 5.40 below).

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. In general 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

¹⁵ Section 1(3) Carers (Recognition and Services) Act 1995 and s1(3) Carers and Disabled Children Act 2000).

‘carers assessment’ and in certain situations to support services from the social services department. The meanings of ‘substantial’ and ‘regular;’ are considered at para 3.21 below. Certain statutory provisions adopt a slightly different definition – for example in relation to flexible working under the Work and Families Act 2006, and in relation to the provision of information in Wales, under the Carers Strategies (Wales) Measure 2010: these are considered separately below, see para 4.77 and para 4.28 respectively.

Disabled elderly and ill people

2.5 The Carers Acts define a carer by reference to his or her caring role in respect of someone who may be entitled to services under the community care legislation or the Children Act 1989. The main group of people entitled to such services are older people, people who are ill (including people whose illness is caused by the misuse of drugs or alcohol – see para 12.8 below) and disabled people. The law defines disabled people (for the purposes of community care / Children Act 1989 legislation¹⁶) as persons who are¹⁷:

blind, deaf or dumb or who suffer from mental disorder of any description, and ... 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) 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, for instance children with hyperactive and attention deficit disorders (sometimes referred to as Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD)) or adults with ‘high functioning’ autism or Asperger’s syndrome. Such people do, however (if professionally diagnosed as having such a condition) fall within the definition. In relation to children with ADHD / ADD, even if there is no such diagnosis, they would fall within the definition of a ‘*child in need*’ (see para 10.8 below).

2.8 In this guide, rather than repeating the phrase ‘elderly ill and disabled people’ on each occasion, for the sake of brevity the generic phrase ‘disabled person’ is used.

¹⁶ 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).

¹⁷ Section 29 National Assistance Act 1948 and section 17(11) Children Act 1989.

Social Services

- 2.9 This guide is predominantly concerned with the obligations of certain types of local authorities towards carers. 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 in England such authorities have been restructured (as a consequence of the Children Act 2004) into Children's Services Departments and Adult Social Services Departments. 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.

3. Social services obligations to carers - overview

Introduction

- 3.1 Since 1986 when carers were first mentioned in social care legislation¹⁸ their official recognition has grown dramatically. In the first 15 years this took the form of initiatives designed to sustain their caring role. In the recent years, however carers have come to be viewed as people who are entitled to direct support rather than being of only indirect relevance.¹⁹ 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, often with little or no pension provision.
- 3.2 It is for this reason that the Carers (Equal Opportunities) Act 2004, the Work and Families Act 2006, the Childcare Act 2006 and the Equality Act 2010 seek to challenge the social exclusion experienced by carers – particularly through the promotion of their employment, training, education and leisure opportunities. This trend is being reinforced by changes to the strategic planning and auditing regimes.

Strategic planning

- 3.3 Health and social services bodies in England and Wales are obliged to prepare strategic plans outlining how they will advance the health and well-being of their populations.
- 3.4 In England local authorities and primary care trusts (shortly to become clinical commissioning groups²⁰) are required²¹ to prepare and publish a Joint Strategic Needs Assessment (JSNA) of the health and social care needs of people within

¹⁸ Section 4 Disabled Persons (Services, Consultation and Representation) Act 1986.

¹⁹ Twigg J. & Atkin K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham describe four different statutory perceptions / responses to carers, namely: 1. the carer as a resource valued only in terms of their ability to provide support for the disabled / older person; 2. the carer as a co-worker whose well-being is addressed solely to ensure that the caring role remains sustainable; 3. the carer as a co-clients entitled to support in their own right; and 4. the superseded carer model – in which situation the care planning process for the disabled / older person aims to dispense with the need for informal care.

²⁰ Section 192 Health & Social Care Act 2012.

²¹ Section 116 Local Government and Public Involvement in Health Act 2007, as amended.

their local area. At the time of writing (August 2012) the Department of Health has yet to issue the final statutory guidance on the key elements of these strategies – but in draft form it has stressed (amongst other things):

- the obligation on health and social services bodies ‘to consider all relevant needs ... including universal advice and the needs of carers’ (page 16)
- the duty when preparing their plans to involve the local community, including ‘people who use services and their carers’ and ‘carer-led organisations (page 18-19)
- the importance of integrated care – and described the essence of what this meant as ‘an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well coordinated around their needs.’ (at page 36)

3.5 Local authorities in England are still subject to a system of ‘targets’ or ‘performance indicators’ although these are now referred to as agreed ‘outcomes’. For 2012/13, the Adult Social Care Outcomes²² require:

- local authorities to demonstrate that they are taking action to enable carers to ‘balance their caring roles and maintain their desired quality of life’ (Domain 1);
- action to ensure ‘earlier diagnosis, intervention and reablement’ so that the disabled person ‘and their carers are less dependent on intensive services’ (Domain 2);
- councils to keep records demonstrating ‘overall satisfaction of carers with social services’; the ‘proportion of people who use services and carers who find it easy to find information about services’; how ‘carers feel that they are respected as equal partners throughout the care process’; and the ‘proportion of carers who report that they have been included or consulted in discussions about the person they care for’ (Domain 3).

3.6 In Wales, in addition to their strategic obligations under the Carers Strategies (Wales) Measure 2010 (see para 4.26 below) local authorities and Local Health Boards (LHBs) are required to have in place Health, Social Care and Well-Being Strategies.²³ The relevant guidance,²⁴ like that in England, stresses the importance of the active involvement of (amongst others) service users and carers in assessing needs and strategy formulation, implementation and review (page 22 -23).

²² Department of Health (2012) Transparency in outcomes: a framework for quality in adult social care The 2012/13 Adult Social Care Outcomes at www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133335.pdf. At page 6 the Framework explains that the results provided by individual councils will be used to ‘support the government’s role in reporting to the public and parliament’ and for ‘benchmarking and comparison between areas’ and part of the annual ‘local account’ that they provide to the Care Quality Commission.

²³ Section 40 NHS (Wales) Act 2006.

²⁴ Welsh Government (2011) *Health Social Care and Well-being Strategy Guidance 2011/12 – 2013/14*. And see also the Social Care and Well-being Strategies (Wales) Regulations 2003.

The general obligations of health and social services authorities in this context are important, not least that they could otherwise become sidelined by the requirements of the 2010 Measure. The Measure requires that Welsh local authorities and health bodies work in partnership to prepare, publish and implement a strategy. LHBs are the lead agency in the development of these strategies – which are primarily concerned with the better provision of information and ‘signposting’ for carers.

- 3.7 Notwithstanding this increased emphasis on carers’ support at the strategic planning level, there is little empirical evidence to suggest that this is translating into support ‘on the ground’ (particularly given the stark statistics cited above – see para 1.5). The strong probability exists that the comments of the Commission for Social Care Inspection remain as pertinent today as they did in 2006, that:²⁵

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.

It is a system that is no longer ‘fit for purpose’: a system that ‘places unfair and unreasonable demands on carers’.²⁶

Overview of current responsibilities

- 3.8 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 or elderly person.
- 3.9 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’.
- 3.10 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 – ie the assessment that social services departments undertake when deciding what support it should provide for a disabled person.

²⁵ CSCI (2006) *The State of Social Care on England 2005-2006* (CSCI December 2006) page iv.

²⁶ House of Commons Health Committee - Third Report Social Care 2010 conclusions para 9 and 18 and at www.publications.parliament.uk/pa/cm200910/cmselect/cmhealth/22/2202.htm

The rights of all carers

- 3.11 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.
- 3.12 The law states²⁷ 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.
- 3.13 In this respect, important policy guidance²⁸ 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’.²⁹ The guidance emphasises that the ‘preferences of carers should be taken into account and their willingness to continue caring should not be assumed’ (see para 4.45 below) 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’.³⁰

Carers who provide a substantial amount of care on a regular basis.

- 3.14 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 care³¹ on a regular basis – even if the person for whom they care is not eligible for services (see para 9.4 below). 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 account³² – and the fact that they have refused

²⁷ The Community Care Assessment Directions 2004

²⁸ *Community Care in the Next Decade and Beyond* (HMSO 1990).

²⁹ Para 3.25 and 3.16 of the above guidance

³⁰ Para 3.28 of the above guidance.

³¹ The meaning of which is considered further at para 3.18 below.

³² Section 8 Disabled Persons (Services, Consultation and Representation) Act 1986

such an assessment should not be 'used as a reason to exclude the carer from assisting with care planning'.³³

- 3.15 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.
- 3.16 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 a '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) a requirement that carers assessments consider whether the carer works or wishes to work and / or is undertaking, or wishes to undertake, education, training or any leisure activity.

Guidance

- 3.17 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 legislation³⁴. 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.³⁵

Guidance on the 1995 Act

- 3.18 The first carer specific 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

³³ The Community Care Directions 2004 Guidance LAC(2004)24 (para 2.2).

³⁴ For a detailed explanation as to the legal status of guidance, see Clements L, and Thompson P (2011) *Community Care and the Law*, Legal Action Group, London 5th edition chapter 1.

³⁵ *R v Islington LBC ex p Rixon* (1998) 1 CCLR 119 at 123.

Office, it was in the same terms as the English guidance.³⁶ 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

3.19 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.³⁷

Generic 2004 guidance.

3.20 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).³⁸ Regrettably, in Wales no guidance on this Act has as yet been issued although in anticipation of the implementation of the Act an additional annex (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’

3.21 People who provide (or intend to provide) ‘*a substantial amount of care on a regular basis*’ are entitled to a separate carer’s assessment. Although the phrase is used in each of the carers Acts, there is no statutory definition as to 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.

³⁶ The guidance can be accessed via the carersnet website at <http://carersworldradio.ihoststudio.com/resdocs.html>

³⁷ 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

³⁸ SCIE practice guide to the Carers (Equal Opportunities) Act 2004 accessible at www.carers.gov.uk/whatsnew.htm. The Guidance 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.

- 3.22 As the guidance notes, not uncommonly ‘there may be more than one carer providing substantial and regular care in each household’.³⁹
- 3.23 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 circumstances:⁴⁰ essentially, therefore, that the word should be used subjectively, and this must also be the case in the context of the Carers Acts.
- 3.24 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 if provided by 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 for 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.
- 3.25 Practice guidance issued under the 2000 Act is particularly helpful in defining what ‘regular and substantial’ care means. The English guidance⁴¹ at para 67-8 (the Welsh guidance⁴² at para 4.11) 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 life long commitment. For others, such as those caring for adults with severe mental health problems, caring can be a sporadic or cyclical responsibility. The carer may not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or actively seeking to prevent, the next crisis. In addition, caring responsibilities may conflict with other family responsibilities, such as parenting or holding down a job. Any assessment of the carer’s need for support has to look at the impact of the whole caring situation.

68 The term ‘substantial and regular’ is not defined in this guidance. In any given situation, the test that a practitioner should apply will relate to the impact of the caring role on the

³⁹ Para 46 Combined Policy Guidance under the 2000 and 2004 Acts (Department of Health 2005) accessible at www.dh.gov.uk/assetRoot/04/11/78/66/04117866.pdf

⁴⁰ See LAC (93) 10 App 4 para 8 ~ in the context of s29 National Assistance Act 1948.

⁴¹ Very similar wording is to be found at para’s 48-49 of the Combined Policy Guidance under the 2000 and 2004 Acts.

⁴² This guidance is also repeated in relation to the 2010 Measure – see Welsh Government (2012) Carers Strategies (Wales) Measure 2010 Guidance issued to Local Health Boards and Local Authorities, Annex 2.

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?

3.26 The assessment of the 'sustainability of the caring relationship' is further considered at para 4.40 below.

'Intending to provide'

3.27 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, which is largely directed at hospital discharges (see para 7.25 below) 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

3.28 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).

3.29 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.

3.30 Not infrequently, a local authority will not be able to decide upon the extent of a carer's responsibilities without undertaking a 'carers' assessment. Where there is uncertainty an assessment should take place. The Local Ombudsman has

been critical of a local authority that refused to undertake a carer's assessment in such a case, commenting:⁴³

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'

3.31 The right to a separate carers assessment is dependent, not only on the provision of a 'substantial amount' of care but also on the requirement that this be 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.²⁰ The Practice Guidance to the 1995 Act⁴⁴ 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

3.32 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.

The personalisation agenda & personal budgets

The Government in England is implementing what it calls a 'personalisation' programme which involves providing disabled elderly and ill people with 'personal budgets' (sometimes referred to as 'individual budgets') which can be taken in the form of cash – in which case they are a 'Direct Payment' (see para 5.35 below) – or they can be managed by the local authority or an intermediary (sometimes referred to as a broker) who help the recipient decide which services to purchase with the allotted budget. The programme is merely a policy initiative of the English Government and does not in any way detract from the community care and carers' rights of those who are offered them.⁴⁵

⁴³ Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004, and see also complaint no. 05/C/11921 (Trafford MBC) on 26 July 2007.

⁴⁴ Para 7 practice guidance LAC (96)7 and WOC 16/96 and WHC (96)21 in Wales.

⁴⁵ In this regard see Clements, L. Bangs, J and Holzhausen, E. (2009) 'Individual Budgets and Carers' at <http://www.lukeclements.co.uk/resources/>.

- 3.33 At its best, the personalisation programme aims to ensure that the support funded or coordinated by the statutory agencies ‘promotes choice, control and independence for carers, tailoring solutions around the individual and the family’. Carer specific guidance concerning the programme has been issued by a number of key bodies, including the Department of Health⁴⁶ and the Social Care Institute for Excellence.⁴⁷
- 3.34 Where a personal budget is being proposed as an additional option for people entitled to community care support services (or carers’ services) users and carers must have genuine choice in deciding whether or not to opt for the budget. Where this option is chosen, the law requires that carers have the same right to decide whether to care and if they chose so to do, the right to decide the extent of their caring role. Where the amount of the budget has been calculated using a standard formula (sometimes referred to as a Resource Allocation System or ‘RAS’) the UK Supreme Court has held that it ‘must equate to the reasonable cost of securing’ the person’s eligible needs.⁴⁸ In such cases authorities must ensure that their systems are sensitive to the needs of carers and sufficiently flexible to respond to the need for:⁴⁹
- different levels of support - ie. cases with special needs are more expensive;
 - short (and indeed ‘longer’) breaks;
 - carers to undertake or to continue with education, training, leisure and employment activities / responsibilities;
 - carers services under the Carers and Disabled Children Act 2000;
 - support for disabled parents so that children and young people are not left with unreasonable levels of caring responsibilities;
 - support in relation to unexpected or exceptional circumstances.
- 3.35 *R (JL) v. Islington LBC* (2009)⁵⁰ is an example of the difficulties that can arise if budget based scheme is implemented inflexibly. Islington claimed its new system allocated service on the basis of ‘need rather than diagnosis’ and did so in a way that was ‘transparent’ and ‘equitable’ (para 13 of judgment). The authority did this by creating three bands with the top band

⁴⁶ Department of Health (2010) ‘Carers, personalisation and outcomes’ – at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122383.pdf

⁴⁷ SCIE Report 40: ‘Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers’ at: www.scie.org.uk/publications/reports/report40/index.asp

⁴⁸ *R (KM) v Cambridgeshire County Council* [2012] UKSC 23 para 22.

⁴⁹ See Clements, L. Bangs, J and Holzhausen, E. (2009) ‘Individual Budgets and Carers’ at <http://www.lukeclements.co.uk/resources/> and Series, L and Clements, L ‘Putting the Cart before the Horse: Resource Allocation Systems and Community Care’ www.lukeclements.co.uk/whats-new/.

⁵⁰ [2009] EWHC 458 (Admin)

providing for 12 hours a week. Although at the hearing the authority claimed that there was discretion in the application of these bands, the judge concluded that this in practice was not the case.

- 3.36 The system had the effect of reducing the applicant's son's care package by 50% - a decrease in respite care from 1,248 to 624 hours a year. The court considered that such a drastic reduction in provision required explicit justification (eg a 'really marked improvement in the child's condition or in family circumstances') and considered that this was lacking (para 36 and para 42). In her judgment (para 39) Black J states:

I find it hard to see how a system such as this one, where points are attributed to a standard list of factors, leading to banded relief with a fixed upper limit, can be sufficiently sophisticated to amount to a genuine assessment of an individual child's needs. There will be times when, fortuitously, the needs assessed by such a system will coincide with the real needs of the family but it is difficult to have any confidence in that occurring sufficiently frequently to justify the use of eligibility criteria on their own.

- 3.37 Furthermore Black J held that the applicant's contention that although the introduction of the new eligibility criteria scheme, may have extended the opportunity for some disabled people (those who are less disabled) it might also have curtailed it for others (the more disabled). Accordingly the local authority were required to produce evidence that it had due regard to its disability equality duty (under what is now s149 Equality Act 2010 - see para 13.26 below) and in the judge's opinion this had not been done. This means that before developing any new eligibility criteria or personal budgets arrangements, a local authority must consider whether it is likely to have a significant change on the entitlement of existing people to services and if so, must assess the extent of this impact, and if it decides to persevere with the new system, it must have cogent reasons why such a change is likely to lead to a general improvement for disabled people and their carers.

Law Reform

- 3.38 In 2012 the Governments in England and in Wales published draft proposals for Bills, which if enacted, would codify and update social care law in their nations. In both cases, the law is unlikely to come into effect until 2014 at the earliest.
- 3.39 In England, the draft Care and Support Bill⁵¹ proposes a single, modern law for adult care and support that replaces existing

⁵¹ Secretary of State for Health (2012) 'Draft Care and Support Bill' London: TSO Cm 8386 at www.dh.gov.uk/health/2012/07/careandsupportbill/

outdated and complex legislation. The draft Bill will be scrutinised by a Parliamentary select committee in 2013, after which the Government can introduce an actual Bill into Parliament. Even if introduced in 2014 and even if this is approved by Parliament that year it would be unlikely to come into force until 2015 or more probably 2016.

- 3.40 The draft Care and Support Bill has been given a qualified welcome by carers' organisations,⁵² particularly the codified duty it would create, requiring local authorities to assess carers without the need for the carer having to make a 'request' or having to establish that he or she is providing 'regular and substantial care' (clause 10).
- 3.41 Concern has, however, been expressed about provisions in the draft Bill which could undermine the current legal and policy framework relating to young carers and these are considered at para 10.17 below.
- 3.42 In March 2012 the Welsh Government published a consultation document entitled 'Social Services (Wales) Bill'.⁵³ This was not a draft Bill but a series of policy statements and questions. The consultation period was brief, closing in June 2012 and the intention is that a Bill be introduced into the National Assembly in October 2012. Given that the Bill proposes a complete overhaul of adult and children's social services law, there must be significant cause for concern over such a short timetable (not least that the Welsh Government has not as yet drafted a primary statute of such scale).
- 3.43 Para 2.6 of the consultation document (which concerns the proposed carers legislative changes) explains that the intention is to 'simplify and clarify the legislation' without in any way diminishing existing rights. The proposal is that there be a single duty on local authorities to offer a carer's needs assessment to a carer (of any age) if they believe that they have a regular and substantial caring role and to carry out an assessment if the carer wants them to do so.' The definition of a carer would also be simplified by bringing it in line with 1(2) of the Carers Strategies (Wales) Measure (see para 4.28 below).

⁵² See for example, Carers UK (2012) 'Draft Care and Support Bill briefing' at www.carersuk.org/professionals/resources/briefings/item/2648-draft-care-and-support-bill-briefing

⁵³ Welsh Government (2012) Consultation document: Social Services (Wales) Bill WG14266 at <http://wales.gov.uk/docs/dhss/consultation/120312consultationen.pdf>

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 (ie personal care, mobility, access, social, recreational needs etc) 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, the carer should have their assessment.
3. The carer's assessment analyses the sustainability of the caring role - primarily whether the carers 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 carers 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 carers 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 2000⁵⁴, 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.

Carers' assessments - timescale

- 4.2 None of the Carers Acts stipulate a period within which a carer's assessment must be commenced or indeed completed. Where a statute does not prescribe a time for something, the courts require that it be done 'within reasonable period' and of course what this is, will depend upon the facts of any particular case. However, in relation to community care assessment the Local Government Ombudsman has stated that s/he 'normally considers that it is reasonable for this to take between four and six weeks from the date of the initial request'.⁵⁵ Given that a carers assessment is almost invariably undertaken as part of this process (and that the outcome of this assessment is to be taken into account when deciding what community care services are provided) it must follow that as a general rule a carers assessment must also be undertaken well within the four and six weeks period.

Delegation of assessments

- 4.3 The duty to assess under the Carers Acts is a social services function which cannot be delegated unless (and unusually), either: (1) the authority has entered into a formal partnership arrangement with an NHS body under s75⁵⁶ NHS Act 2006 (formerly s31 Health Act 2001); or (2) the local authority and the delegated body are part of an 'adult social work practice pilot scheme' established by the secretary of state.⁵⁷ Apart

⁵⁴ Para 24-7; and para 4.3 of the Welsh guidance.

⁵⁵ Local Government Ombudsman (2011) Fact Sheet S4 'Complaints about councils that conduct community care assessments' at <http://www.lgo.org.uk/publications/fact-sheets/complaints-about-community-care-assessments/>

⁵⁶ NHS (Wales) Act 2006 s33.

⁵⁷ The Contracting Out (Local Authorities Social Services Functions) (England) Order 2011 SI No 1568 permits delegation of social services functions in England in very limited conditions – namely where the secretary of state has established an 'adult social work practice pilot scheme'; it also permits the delegation of community care assessments where a pilot 'in control' site has been established – provided the local authority is one listed in the Schedule to the Community Care Services: Disabled

from these limited situations, 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.

- 4.4 This analysis is endorsed by 2010 guidance⁵⁸ which, suggested that councils may arrange for the actual process of carrying out the assessment to be undertaken by voluntary organisations – but only if the council ‘funds the organisation to undertake assessments and checks the process and outcomes of each assessment.’
- 4.5 The guidance to the Carers Strategies (Wales) Measure 2010 (considered at para 4.27 below) states (para 3.4) that the ‘Carers and Disabled Children Act 2000 provides for Local Health Boards to undertake Carers needs assessments’. The provenance of this statement is by no means obvious as there does not appear to be anything in the 2000 Act to this effect.

The carer must request the assessment

- 4.6 The right to a carers 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’.⁵⁹ 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’.

People's Choice and Control (Pilot Scheme) (England) Directions 201, currently (it appears) Birmingham City Council; Lambeth LBC; North East Lincolnshire Care Plus Trust; Shropshire County Council; Suffolk County Council and Surrey County Council..

⁵⁸ Health and Social Care Information Centre (2010) Referrals, Assessments and Packages of Care in Adult Personal Social Services accessible at the NHS Information Centre for Health and Social Care at <http://www.ic.nhs.uk/>

⁵⁹ Carnwath J in *R v Gloucestershire County Council ex p RADAR* (1995) 1CCLR 476; [1996] COD 253.

The duty to inform

- 4.7 Although carers consistently rate the provision of information as one of their top priorities, 2003 research suggested that many of them were not even advised of their right to an assessment when the person they care for is being assessed.⁶⁰ 2009 research (concerning Individual Budgets – see para 3.33 above) shows that problems remain: finding that even where carers were offered an assessment, these did ‘not always comply with current legislation’.⁶¹
- 4.8 Although there are over six million carers in the UK, what is not generally appreciated is that this is a constantly changing group of individuals with approximately 2 million adults becoming (and ceasing to be) carers every year.⁶² It follows that at any one time the impact of caring will affect many more than the six million people - 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’⁶³ of great importance since it is likely that many of the ‘new carers’ will be unaware of their rights, or of the support available.⁶⁴ Likewise, many of those ceasing to be carers may be in need of information concerning their options – for example the availability of employment, training and benefits advice.
- 4.9 The obligation to inform carers can be divided into (1) the duty owed to an individual carer (ie a ‘specific’ duty) and (2) a broader duty to ensure that carers in general are properly informed of their entitlements. These two categories are considered separately below.

The specific duty

- 4.10 Section 1 Carers Equal Opportunities Act 2004 places a duty on English and Welsh social services authorities to inform individual carers of their right to a carers assessment.⁶⁵ This duty arises when the social services department is either:

⁶⁰ Carers UK (2003) *Missed Opportunities The impact of new rights for carers* and see also para 19 Combined Policy Guidance under the 2000 and 2004 Acts which found that almost half of the carers interviewed had not been offered an assessment; and see also Department of Health (Social Services Inspectorate), *Independence Matters*, December 2003, para 5.25, p33

⁶¹ Glendinning C and others (2009) *Individual Budgets: Impacts and outcomes for carers* Social Policy Research Unit, York Executive Summary p1.

⁶² Hirst, M (2001) *Caring Relationships Over Time* SPRU, University of York.

⁶³ Para 31 Combined Policy Guidance under the 2000 and 2004 Acts.

⁶⁴ 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’.

⁶⁵ 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

- a) carrying out a community care or Children's Act assessment of a disabled person or is:
- b) contemplating undertaking such an assessment.⁶⁶
- 4.11 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.
- 4.12 Local authorities should aim to make their 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'.⁶⁷
- 4.13 There is no 'duty to inform' if the carer has recently been advised of his/her rights in another context (for instance a carers assessment has recently been undertaken or the carer has had a shortened carers assessment has been undertaken as part of a hospital discharge of the person for whom they care⁶⁸ - see para 7.37 below).
- 4.14 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'⁶⁹ 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 carers guide to a carers assessment*'.⁷⁰

The general obligation to 'inform' carers

- 4.15 The nature and extent of the information that English and Welsh social services departments and NHS bodies (in Wales) are required to give to carers, is wide ranging. As the succeeding paragraphs explain, these obligations stem from a variety of statutory and subordinate legislative sources. Given

2B) and by amending section 6 of the 2000 Act (by inserting a new section 6A). A statutory duty of this nature also exists in Scotland s11(2) Community Care (Scotland) Act 2002.

⁶⁶ But has not as yet completed one (for instance because the disabled person is refusing to cooperate with the assessment).

⁶⁷ Para 20 Combined Policy Guidance under the 2000 and 2004 Acts.

⁶⁸ Section 4(3) of the Community Care (Delayed Discharges etc.) Act 2003

⁶⁹ LAC (96)7 at para 20 and WOC 16/96 and WHC (96)21 in Wales.

⁷⁰ Para 9 Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Policy Guidance. In Wales para's 4.12 and 4.13 of the Welsh Assembly 'Practitioners Guide to Carers' Assessment' Guidance requires that social services departments notify potential carers' of their right to an assessment and that they be given a leaflet *A carers guide to a carers assessment*.

this complex of duties, there is considerable force in the practice guidance advice (see para 4.23 below) that authorities develop, in effect, ‘one stop shops’ or similar mechanisms to ensure that wide ranging advice is made available to carers.

The general social services duty obligation to ‘inform’ carers

4.16 Technically carers in England and Wales have the right to be informed of their right to make two separate requests.⁷¹

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.

4.17 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.

4.18 In order to consider these matters the assessor will need to know what facilities exist and 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.

⁷¹ Although in practice carers are not likely to be overly concerned about which legislation applies; outcomes being far more important for many carers.

- 4.19 The obligation on social services departments is reinforced by guidance on the Community Care Assessment Directions 2004⁷² 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.

- 4.20 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 duty⁷³ 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.'

- 4.21 Follow up guidance also stressed the importance of information provision⁷⁴ 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.

- 4.22 The general duty upon 'social services with their partners in housing and health' to inform was strengthened by the 'Better Care, Higher Standards' policy guidance.⁷⁵ 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.

⁷² LAC (2004) 25 August 2004 at para 2.6

⁷³ DHSS Circular 12/70 at para 5

⁷⁴ Care Management and Assessment – A Practitioners' Guide (HMSO 1991) at para 1.3.

⁷⁵ LAC (2001)6 : HSC 2001/006 para 2 and 19B, issued under s7(1) LASSA 1970. The 'Charters are for anyone 18 or over in England who has difficulties associated with old age, long term illness or disability and for carers who support people in these circumstances' (p1). Additionally see the DETR guidance at www.dh.gov.uk/assetRoot/04/05/14/15/04051415.pdf

4.23 The practice guidance to the 2004 Act advises that a carers information strategy should (amongst other things)⁷⁶:

- 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 peace 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

and

- 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

4.24 The need for carers to be properly informed has the potential to conflict with the ‘confidentiality’ rights of those for whom they care. This question is considered further at para 14.09 below.

4.25 Local authorities in Wales have additional ‘carer information provision’ obligations, by virtue of the Carers Strategies (Wales) Measure 2010. Since the Local Health Boards (LHBs) are the lead organisation for the development and implementation of these strategies, this question is considered in the section that follows.

The general duty on Welsh NHS bodies to ‘inform’ carers

4.26 The Carers Strategies (Wales) Measure 2010⁷⁷ required every LHB to submit to the Welsh Government by November 2012 a draft strategy through which the LHB proposes to:

- improve early identification of carers;
- improve carers’ access to information & services to protect their mental & physical health
- ensure that carers receive earlier and more planned support from the NHS, LA’s & independent sectors;

⁷⁶ SCIE practice guide to the Carers (Equal Opportunities) Act 2004.

⁷⁷ The Measure derives from a similar initiative in the Community Care and Health (Scotland) Act 2002.

- 4.27 The detail of the Measure is fleshed out by Regulations⁷⁸ and guidance.⁷⁹ The Measure applies to all carers (adults and children), and although LHBs are the lead body, they are required to prepare the strategy in conjunction with their partners. The principal partners are local authority adult and children social services departments – but the regulations require extensive consultation and involvement with ‘Carers, patients, NHS staff, local authorities, the Third sector, the private sector and other relevant groups’ (regulations 4 and 7, & guidance para 3.6). The guidance makes clear that the information provision obligations created by the measure are in addition to those required by other legislation (para 3.4).
- 4.28 Although the guidance urges LHBs to extend their information and support activities to all carers (para 3.15), section 1 of the Measure defines a carer (and hence those for whom the core entitlements apply) as ‘an individual who provides, or intends to provide a substantial amount of care on a regular basis for - (a) a disabled child; or (b) an individual aged 18 or over. It follows that there is no requirement (in relation to an adult) that he or she is a disabled, elderly or ill person or someone who might be entitled to community care services. The guidance (Annex 2 page 36) amplifies what is meant by a ‘substantial amount of care on a regular basis’ and in so doing adopts the same phrasing as the guidance to the Carers & Disabled Children Act 2000 (considered at para 3.25 above).
- 4.29 The Measure is heavy on ‘process’ (which is spelt out in the regulations) in the sense that it requires each of the seven LHBs to prepare a draft strategy documents (which will be vetted, possibly amended and approved by the Welsh Government). Each strategy will last for 3 years (and then have to be renewed); will be subject to review after 18 months; and every year each LHBs must produce a report ‘explaining how they are implementing and monitoring their strategy’ (regulations 8 and 9). Regulation 5 summarises the key elements of such strategies, requiring that LHBs must include provision about —
- how they will engage general medical practitioners in the implementation of the strategy;
 - training for staff ;
 - the means by which, and the languages in which information for carers will be made available.

⁷⁸ The Carers Strategies (Wales) Regulations 2011 No. 2939 (W.315) as amended by the The Carers Strategies (Wales) (Amendment) Regulations 2012 No. 282 (W.46).

⁷⁹ Welsh Government (2012) Carers Strategies (Wales) Measure 2010: Guidance issued to Local Health Boards and Local Authorities.

- 4.30 Regulation 6 then provides an extensive list of what information and advice needs must be addressed in the strategy, namely:
- a. information about carers' rights which includes reference to carers of those whose needs relate to their mental health;
 - b. information about medication and its potential side effects;
 - c. information on the medical condition and course of treatment of persons cared for;
 - d. information to assist children and young people who have a caring role;
 - e. information on the availability, entitlement to and sources of local and national support including—
 - short breaks and respite care; carer's needs assessment; the Court of Protection; direct payments; housing support; independent advocacy; counselling including bereavement support; guardianship; age appropriate support groups; culturally appropriate support groups; financial advice and support including advice on welfare benefits; managing the financial and administrative affairs of persons who are cared for.
 - f. information and advice on employment provisions, including flexible working;
 - g. information on the duties of local authorities to assess the needs of those who may be eligible for community care services and to assess the needs of carers, and, in both cases, provide services
 - h. information about the availability of concessionary transport schemes and other patient transport arrangements to enable carers to attend NHS appointments with the person cared for;
 - i. information and advice on physical aids, and housing adaptations;
 - j. information on the regulation and inspection of health and care services by the Healthcare Inspectorate Wales and the Care and Social Services Inspectorate Wales;
 - k. information on local carer support agencies and appropriate national organisations supporting patients, users and carers;
 - l. information on how to avoid hospital admission;
 - m. information on the availability of crisis support and how to access it;
 - n. information on the availability of re-ablement and intermediate care for the person cared for;
 - o. information that helps promote health and well-being (including information and training on stress management techniques, healthy diet and physical exercise);
 - p. information on the complaints procedures of the Local Health Board and the local authorities;
 - q. information on programmes to assist carers to carry out their caring role safely and effectively, to include but not limited to—
 - safe lifting, moving and handling; medicines management including the safe administration of medication to the carer or person cared for; relevant nursing skills; use of aids and adaptations; continence care; stress management; assistance with eating and drinking; dealing with behavioural issues of the person cared for; helping carers to look after themselves.

- 4.31 Only time will tell as to whether the noble aims underpinning the strategy will result in material gains for carers – or merely create a new industry of administrative officers drafting and updating glossy strategy documents, collecting data and publishing annual reports. The hope must be that the Measure produces a cultural change in the way that the NHS sees carers: not as people whose presence justifies accelerated hospital discharge of their nearest and dearest, or a reduced level of community based health care – but people who (as the guidance emphasises) are key partners (para 2.1); whose willingness to care must never be assumed (para 3.20); and who require support to fulfil their roles, such as information, training, financial and emotional support, equipment and adaptations and breaks from caring (para 1.16).

The setting and format of the assessment

Private meeting

- 4.32 Guidance under both the 1995 and 2000 Acts emphasise 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 private⁸⁰ discussion in which carers can candidly express their views’.⁸¹ The 2000 Act guidance takes this right further by advising that in order that the carer have an opportunity to opt for a confidential meeting, the assessor is advised to make arrangements for the assessment ‘over the phone, and away from the home or while the cared for person is out’.⁸²

Advocacy / support

- 4.33 Social services should ensure that carers are aware that they can have a friend or advocate present at their assessment.⁸³ Commonly this may take the form of a Carers Support Worker from a carers centre attending to provide practical or merely

⁸⁰ Authorities will need to ensure that the carer is aware that his or her comments may be placed on the user’s file and accordingly advised of the right to withhold consent to them being copied to the user.

⁸¹ Practice Guidance LAC (96)7 and WOC 16/96 and WHC (96)21 in Wales – para 9.1.

⁸² Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 59 and the Welsh Assembly publication ‘Guidance 2000 Act’ 3.11.

⁸³ Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 60 and the Welsh Assembly publication ‘Guidance 2000 Act’ 3.11.

moral support. It may however range from a family friend to a specialist advocate.

The actual assessment process

4.34 Although both the 1995 and the 2000 Acts contain provisions enabling 'directions' to be issued by the Secretary of State / Welsh Assembly⁸⁴ 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 guidance⁸⁵ 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 private⁸⁶ discussion in which carers can candidly express their views

4.35 Guidance under the 2000 Act provides significantly more assistance in detailing the key attributes and approach of a carer's assessment.⁸⁷ 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'.⁸⁸

4.36 Not infrequently social services departments have handed carers a questionnaire which they have then been asked to complete themselves (a practice that appears to be increasing with the personalisation programme).⁸⁹ This process is acceptable, provided (1) the carer is agreeable; and (2) the local authority appreciates that this is not an assessment – merely a preliminary stage; and (3) 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'.⁹⁰ This means that carers should always be informed – not only that they have the right to a face-to-face

⁸⁴ Section 1(4) Carers (Recognition and Services) Act 1995 and s1(4) Carers and Disabled Children Act 2000.

⁸⁵ For adult carers at para's 9-11 and for young carers at para 16.

⁸⁶ Authorities will need to ensure that the carer is aware that his or her comments may be placed on the user's file and accordingly advised of the right to withhold consent to them being copied to the user.

⁸⁷ In England as the *Practitioners Guide to Carers' Assessments under the Carers and Disabled Children Act 2000* and in Wales as the *Practitioners Guide to Carers' Assessment*.

⁸⁸ Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 47.

⁸⁹ In this regard see 'Individual Budgets and carers' at www.lukeclements.com – 'what's new'.

⁹⁰ Practice guidance para 61

meeting for their assessment (in private) – but also that this is the ‘norm’.

- 4.37 Specific guidance exists in both England and Wales⁹¹ 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’.⁹²
- 4.38 ‘Focussing on outcomes’ means that the assessment should identify the type of life / living arrangements that carer seeks, rather than merely the services that might be provided. It means that 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 Carers Assessment ~ key issues

- 4.39 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.⁹³

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

⁹¹ In England as the *Practitioners Guide to Carers’ Assessments under the Carers and Disabled Children Act 2000* and in Wales as the *Practitioners Guide to Carers’ Assessment*.

⁹² para 29 *Practitioners Guide to Carers’ Assessments under the Carers and Disabled Children Act 2000* and para 3.6 of the Welsh Guidance.

⁹³ Section 1 Carers (Recognition and Services) Act 1995

- (b) is undertaking, or wishes to undertake, education, training or any leisure activity.⁹⁴

Sustainability

4.40 The 1995 Act requires an assessment of the carer's 'ability to provide and to continue to provide care'. As noted above (see para 3.25 above) the practice guidance issued under the 2000 Act advised that.⁹⁵

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?

4.41 The English practice guidance to the 2000 Act⁹⁶ suggests that in determining what is 'sustainable' four crucial dimensions of the carers' experience should be considered⁹⁷ namely:

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

4.42 These four domains derive from guidance issued to social services departments concerning the assessment of disabled people and originally known as the FACS guidance (Fair Access to Care Services Guidance on Eligibility Criteria for Adult Social Care).⁹⁸ The following section considers each of these domains.

⁹⁴ Section 2 Carers (Equal Opportunities) Act 2004.

⁹⁵ Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 68.

⁹⁶ Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 60.

⁹⁷ This following two paragraphs do not appear in the Welsh Guidance. The Welsh guidance on Carer's Assessments does however expand upon the concept to a limited degree at para.2.4.4 as does the Welsh Assembly Government's (2002) Guidance *Creating a Unified and Fair System for Assessing and Managing Care* at paragraph 2.36.

⁹⁸ But now replaced by Department of Health (2010) guidance entitled *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010* para 54 and in Wales in the Welsh Assembly Government's (2002) guidance *Creating a Unified and Fair System for Assessing and Managing Care* at para 5.16

Autonomy / choice

- 4.43 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 financially 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.
- 4.44 The practice guidance to the 2000 Act⁹⁹ 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
- 4.45 The practice guidance to the 1995 Act¹⁰⁰ reiterated advice in 1990 community care policy guidance (see para 3.13 above) 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.
- 4.46 The above emphasis on ‘willingness’ echoes the binding policy guidance (2010) issued by the Department of Health¹⁰¹, that in undertaking a community care assessment ‘no assumptions should be made about the level and quality of support available from carers’. This point is picked up at para 90 of the same guidance¹⁰² in terms that community care assessments ‘should not unfairly discriminate against individuals’ on (amongst other grounds) ‘personal relationships, or living and caring arrangements’.

⁹⁹ Practice guidance to the 2000 Act (para 69)

¹⁰⁰ LAC (96)7 at para 9.8 WOC 16/96 and WHC (96)21 in Wales. At para 9.8

¹⁰¹ Department of Health (2010) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010* para 95.

¹⁰² In Wales, at para 2.33 of the Unified and Fair System for Assessing and Managing Care’ (UFSAMC) 2002.

- 4.47 The Guidance accompanying the Carers Strategies (Wales) Measure 2010¹⁰³ expresses the same point in the following terms (para 3.20):

It must never be assumed that carers can or will provide care. Carers can choose whether or not they will care and the level of support they are prepared to offer. The amount of caring they can and are willing to provide must be negotiated and regularly reviewed

- 4.48 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 Act¹⁰⁴ 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 carers¹⁰⁵ 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

- 4.49 The practice guidance to the 2000 Act¹⁰⁶ describes 'an extensive loss of autonomy' as a 'critical risk' for a carer (see para 4.91 below) – 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 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'.¹⁰⁷

Health and Safety.

- 4.50 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

¹⁰³ Welsh Government (2012) Carers Strategies (Wales) Measure 2010: Guidance issued to Local Health Boards and Local Authorities.

¹⁰⁴ LAC (96)7at para 9.3 WOC 16/96 and WHC (96)21 in Wales. For adult carers at paras 9-11.

¹⁰⁵ Atkin, K. (1992) 'Similarities and Differences Between Informal Carers', in *Carers: Research and Practice* (HMSO).

¹⁰⁶ Practice guidance to the 2000 Act (para 70) – and see Table 1 below.

¹⁰⁷ Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 69.

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.

4.51 There is substantial evidence to suggest that significant caring responsibilities can be harmful. A Princess Royal Trust for Carers' report (2002)¹⁰⁸ 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

4.52 A similar study by Carers UK¹⁰⁹ 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).

4.53 The practice guidance to the 2000 Act¹¹⁰ and the binding 2010 policy guidance¹¹¹ describe 'the development of major health problems' as a 'critical risk' for a carer – ie one that demands a response by the local authority (see also para 4.91 below). 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).

¹⁰⁸ Princess Royal Trust for Carers, *Carers Speak Out Project: Report on findings and recommendations*, October 2002

¹⁰⁹ Carers UK, *Missed Opportunities: the impact of new rights for carers*, June 2003.

¹¹⁰ Practice guidance to the 2000 Act (para 70) – and see Table 1 below.

¹¹¹ Department of Health (2010) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010* para 102.

Duty to safeguard health of carers

- 4.54 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.¹¹² 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 unreasonable risk of harm.
- 4.55 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 (eg 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.
- 4.56 Although carers are not 'employees' for the purposes of the 'manual handling regulations'¹¹³ and other health and safety at work legislation, they are persons to whom the authority owe 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).

Safeguarding of adults and children

- 4.57 Social services departments have lead responsibility for the protection of children in need and of vulnerable adults. Analysis of the nature and extent of these responsibilities is a subject that lies outside the scope of this text. However on occasions the courts and ombudsmen have considered that the statutory authorities have misunderstood and misused their safeguarding powers (and this issue is considered further at para 13.06 below). In describing this particular problem Lord Justice Munby observed:¹¹⁴

... carers, look to the State – to a local authority – for the support, the assistance and the provision of the services to which

¹¹² This will frequently include the manual handling risks posed to carers *R (Ireneschild) v Lambeth LBC* [2006] EWCA Civ 2354 (Admin.)

¹¹³ Manual Handling Operations Regulations 1992 SI No 2793. However by section 3(1) Health and Safety at Work etc. Act 1974 there is a general duty of care on employers to people not in their employment – albeit that this is a penal provision – see *R (Hampstead Heath Winter Swimming Club) v. Corporation of London* [2005] EWHC 713 (Admin) [2005] 1 W.L.R. 2930; and see generally, L Clements and P Thompson (2011) *Community Care and the Law* 4th edn para 4.126.

¹¹⁴ *A Local Authority v A (A Child)* [2010] EWHC 978 (Fam).

the law, giving effect to the underlying principles of the Welfare State, entitles them. They do not seek to be “controlled” The State, the local authority, is the servant of those in need of its support and assistance, not their master. ...

Managing daily routines and ‘involvement’

- 4.58 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 the same must hold true for their carers.
- 4.59 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 their freedom ‘to maintain relationships, employment, interests and other commitments alongside their caring responsibilities’.¹¹⁵
- 4.60 Whilst the carers assessment process tends to focus on certain key ‘daily routines’ indicators it is important to aware that there are a wide range of relevant factors impacting on carers, not least, anxiety about debt – in relation to which a 2007 Carers UK report¹¹⁶ found that 72% of carers were worse off since they started caring, 54% had had to give up work to care, 53% said that financial worries were affecting their health and 33% were in debt. Similar findings emerge from 2010 research undertaken by Contact a Family, which found that due to financial difficulties, 23% of parent carers were going without heating, 14% without food and 73% without leisure and days out.¹¹⁷
- 4.61 The practice guidance to the 2000 Act¹¹⁸ and the binding 2010 policy guidance¹¹⁹ state 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’ (see also para 4.88. and 4.91 below).

¹¹⁵ Practice guidance to the 2000 Act (para 69)

¹¹⁶ Carers UK (2007) Real change not short change.

¹¹⁷ Contact a Family, *Counting the Costs* (2010)

¹¹⁸ Practice guidance to the 2000 Act (para 70) – and see Table 1 below.

¹¹⁹ Department of Health (2010) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England* 2010 para 102.

- 4.62 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 (see also, in this context, para 4.88 below).

Employment, training education and leisure activities

- 4.63 The above categorisation of a risk to employment or other responsibilities as a 'critical risk' is also to be found in' in carer-specific guidance and statute. In respect of the former, the practice guidance to the 2000 Act (at para 35) states:

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

- 4.64 Section 2 Carers (Equal Opportunities) Act 2004 provides statutory recognition of this right, by obliging 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.

4.65 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:¹²⁰

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.

4.66 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 4.7 above for local authority ‘carer information obligations’.

4.67 A Welsh Ombudsman’s report¹²¹ provides an example of the new emphasis on carers’ right to work. Relying heavily on the obligations created by the 2004 Act the Ombudsman was highly critical of a local authority that failed to provide direct payments to a parent who wished to use them to purchase respite care so that he could pursue his University’s studies – in the Ombudsman’s opinion there was an obligation on the local authority to ensure that the parent was not ‘disadvantaged in pursuit of education/training any more than other parents’.

4.68 Carers’ employment rights also benefit from the protection the protection provided by the Equality Act 2010 and this question is considered at section 13 below.

¹²⁰ The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): Standing Committee C 10 March 2004 Column No. 7.

¹²¹ Public Service Ombudsman (Wales) Complaint No. B2004/0707/S/370 against Swansea City Council 22 February 2007 see in particular paras 78, 133 &137.

Promoting carers' employment

- 4.69 The Department of Health's 2001 report *Carers and Employment*¹²² 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 2004¹²³ noted that in such cases 'the assumption was often made that there was no choice but that the carer should give up work'. This approach is no longer lawful.
- 4.70 Very significant numbers of carers are of working age – possibly 80%.¹²⁴ 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 result.¹²⁵ A number of research reports have found that carers repeatedly stress the value of being able to go out to work¹²⁶ and that possibly 80% would return to work if they could.¹²⁷ It appears, that caring is not only damaging to the health of many carers (see para 4.39 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 hours.¹²⁸
- 4.71 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 11 below.¹²⁹

Emergency leave employment rights

- 4.72 Carers have limited rights to take (unpaid) time off work to care for a dependent. This right is found in section 57A(1) Employment Rights Act 1996¹³⁰ 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-

¹²² Carers and Employment: Report on Visits to Five Councils with Social Services Responsibilities, para 2.1, accessible at www.carers.gov.uk/visito5councils.pdf

¹²³ Carers (Equal Opportunities) Bill: Research Paper 04/13 by Tim Jarrett & Adam Mellows-Facer 3/2/04 accessible at www.parliament.uk/commons/lib/research/rp2004/rp04-013.pdf

¹²⁴ Office of National Statistics, *Census 2001*

¹²⁵ Carers National Association (now Carers UK) (2000) *Caring on the Breadline: The financial implications of caring*

¹²⁶ Jan Clark, *Independence Matters: An overview of the performance of social care services for physically & sensory disabled people*, Social Services Inspectorate, 2003.

¹²⁷ *The True Cost of Caring, Caring Costs*; Carers National Association, 1996.

¹²⁸ *Caring Costs*, (as above)1996.

¹²⁹ 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.

¹³⁰ Inserted by s8 and Schedule 4 Part II of the Employment Relations Act 1999.

- (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

4.73 'Dependant' is defined widely in relation to persons who live in the same household¹³¹ 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.¹³² 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 (unless the employment terms permit payment).

*Parental Leave*¹³³

4.74 Parents who have worked for their employer for more than a year and are responsible for a child born on or after 15 December 1999 are entitled to parental leave of up to 18 weeks for disabled children (defined as those for whom Disability Living Allowance is paid) or of up to 13 weeks for children under five for whom no DLA is paid. The leave can be taken in periods of up to 4 weeks a year and is usually unpaid (unless the employer operates a special scheme).

Flexible working rights

4.75 Parents with disabled children under 18 and people with caring responsibilities for adults,¹³⁴ who have worked for their employer for at least 26 weeks have the right to apply for flexible working arrangements.¹³⁵ Employers have a statutory

¹³¹ s57A (3) Employment Rights Act 1996.

¹³² s57A (2) Employment Rights Act 1996.

¹³³ See generally the Maternity and Parental Leave etc. Regulations 1999 SI 3312 and Maternity and Parental Leave (Amendment) Regulations 2001 SI 4010.

¹³⁴ By virtue of s12 Work and Families Act 2006.

¹³⁵ s47 Employment Act 2002 (which amended Employment Rights Act 1996 primarily by way of the insertion of a new Part 8A to that Act) and see generally the ACAS guidance on flexible working at <http://www.acas.org.uk/index.aspx?articleid=1616> with the application for flexible working forms at

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 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.

- 4.76 The procedure for requesting flexible working rights is governed by detailed regulations.¹³⁶ These require that the employee submits a carefully considered application. ACAS has produced leaflets which provide a detailed explanation of the process, its timescales and the contents of the application that must be made.¹³⁷ 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.
- 4.77 The regulations¹³⁸ define a 'carer' for the purposes of the 2006 Act as an employee who is or expects to be caring who:
- a) is married to, or the partner (including a civil partner) of the employee; or
 - b) is a relative of the employee; or
 - c) falls into neither category (i) nor (ii), but lives at the same address as the employee.
- 4.78 Relative is defined¹³⁹ as including a mother, father, adopter, guardian, special guardian,¹⁴⁰ parent-in-law, step-parent, son, step-son, son-in-law, daughter, step-daughter, daughter-in-law, brother, step-brother, brother-in-law, sister, step-sister, sister-in-law, uncle, aunt or grandparent, and includes adoptive

<http://webarchive.nationalarchives.gov.uk/+http://www.berr.gov.uk/whatwedo/employment/workandfamilies/flexible-working/flexforms/index.html>.

¹³⁶ The Flexible Working (Eligibility, Complaints and Remedies) Regulations 2002 S.I. 3236 as amended by The Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2006 S.I. 3314, The Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2007 S.I. 1184 and The Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2009 No. 595.

¹³⁷ ACAS has produced two guidance notes: (1) *Advice leaflet - The right to apply for flexible working, A short guide for employers, working parents and carers* accessible at www.acas.org.uk/index.aspx?articleid=803 and (2) a more detailed guidance note *Flexible working and work-life balance* accessible at www.acas.org.uk/media/pdf/i/t/B20_1.pdf and see also *Carers UK Carers and Employment: A guide to the right to request flexible working* at http://www.carersuk.org/media/k2/attachments/UK9019_Flexible_working_guide.pdf.

¹³⁸ The Flexible Working (Eligibility, Complaints and Remedies) Regulations 2002 S.I. 3236 regulation 3B (as amended).

¹³⁹ The Flexible Working (Eligibility, Complaints and Remedies) Regulations 2002 S.I. 3236 regulation 2 (as amended).

¹⁴⁰ A person appointed as a special guardian under section 14A of the Children Act 1989

relationships and relationships of the full blood or half blood or, in the case of an adopted person, such of those relationships as would exist but for the adoption.

- 4.79 The obligation on an employer to consider a request for flexible working is not inconsiderable. A refusal (which must be based on a recognised business ground) can be challenged in an Employment Tribunal, not only by reference to the Flexible Working (Eligibility, Complaints and Remedies) Regulations but also, potentially, as constituting unlawful discrimination based on disability (see para 13.22 below) and (if the employee is a woman) as unlawful sex discrimination since such a practice would disadvantage women more than men, because more women than men are carers.¹⁴¹
- 4.80 Evidence obtained by the Chartered Institute of Personnel and Development (CIPD)¹⁴² suggests that flexible working is not a burden on employers, demonstrating ‘beyond any doubt that the fears expressed about the impact of extending the right to request flexible working are grossly exaggerated’.¹⁴³

Promoting carers’ involvement in education, training and leisure activities

- 4.81 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.¹⁴⁴
- 4.82 The importance of promoting participation in education and training has special resonance, with the determination of successive Governments to challenge social exclusion and to promote full employment.¹⁴⁵ For many carers, their caring role may not be prolonged; indeed the research suggests that every year approximately 2 million adults become carers¹⁴⁶ and approximately the same number cease to be carers.¹⁴⁷ In order that they have the opportunity to regain full employment without

¹⁴¹ see for example, Palmer, C. (2007) *New rights at work for parents and carers from April 2007* Legal Action April 2007 33-35 at 35

¹⁴² CIPD (2011) Press Release New tribunal statistics show right to request flexible working carries no red tape burden for business 3 November 2011 at <http://www.cipd.co.uk/pressoffice/press-releases/new-tribunal-statistics.aspx>

¹⁴³ See also CIPD (2012) Flexible working provision and uptake [www.cipd.co.uk/binaries/5790%20Flexible%20Working%20SR%20\(WEB2\).pdf](http://www.cipd.co.uk/binaries/5790%20Flexible%20Working%20SR%20(WEB2).pdf)

¹⁴⁴ Section 2 Carers (Equal Opportunities) Act 2004

¹⁴⁵ *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 ¼ are people with caring responsibilities

¹⁴⁶ *Caring Relationships Over Time*, Michael Hirst, SPRU, University of York, 2001

¹⁴⁷ Carers National Association (now Carers UK) (2000) *Caring on the Breadline: The financial implications of caring*

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.

- 4.83 Despite Governmental concerns in this field, certain benefit provisions undermine the ability of carers to access education. Carers, for instance face a double penalty: not only is Carers Allowance is withdrawn if they study for more than 21 hours a week, but also the Allowance is not included in the list that generally entitles the student to a fee remission.¹⁴⁸
- 4.84 To consider properly 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 4.23 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. These 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.
- 4.85 In this context, the practice guidance to the 2004 Act notes¹⁴⁹ 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)¹⁵⁰:

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.

¹⁴⁸ See Learning Skills Council (2009) *Including Carers: Towards a Framework for Meeting the Needs of Carers in Further Education and Adult Learning*, Coventry LSC, July 2009 paras 108 – 111 and House of Commons (2008) *Valuing and Supporting Carers*, London TSO at para 46.

¹⁴⁹ SCIE practice guide to the Carers (Equal Opportunities) Act 2004 accessible at

<http://www.scie.org.uk/publications/guides/guide09/index.asp>

¹⁵⁰ Combined Policy Guidance under the 2000 and 2004 Acts (Department of Health 2005).

Eligibility Criteria and Carers Assessments

4.86 The binding English policy guidance, '*Prioritising need in the context of Putting People First*' (2010)¹⁵¹ (para 99) 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:

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.

4.87 Although the grading system is modelled on that which regulates disabled people's assessments (see para 6.4 'stage 2' below) the consequences of a categorisation are different. If a disabled person's is assessed as having a 'substantial' or 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 'substantial' or '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').

4.88 However, as a matter of public law, the categorising of a risk to the sustainability of a caring role as 'critical' or 'substantial' brings with it an obligation by the authority to take steps to ensure that support is made available so that this state of affairs does not continue (or come to pass). Although in such a situation the local authority is not obliged to provide the carer with services¹⁵² 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. This proposition has been stated by the Commission for Social Care Inspection in the following terms:¹⁵³

there is a duty to address carers' eligible needs but discretion about whether to meet these through carers services or community care services – however, some practitioners appear to think [incorrectly] the discretion is about whether to help carers

¹⁵¹ Department of Health (2010) at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154 which draws on the Practice Guidance to the 2000 Act (para 70).

¹⁵² Unless the facts are severe, for example there is a risk to the carer under the European Convention on Human Rights – see the above cited *Prioritising need in the context of Putting People First* guidance at para 100.

¹⁵³ Commission for Social Care Inspection (2008) *Cutting the cake fairly: CSCI review of eligibility criteria for social care*. CSCI, Newcastle para 3.22

- 4.89 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 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).
- 4.90 The judgement in *R (Hughes) v Liverpool City Council* (2005)¹⁵⁴ 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 – see para 13.03 below). 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 censured the actions of the local authority and required it to take rapid steps to remedy its shortcomings. 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.
- 4.91 As noted above, binding English policy guidance, '*Prioritising need in the context of Putting People First*' (para 99) provides eligibility criteria (banded into critical, substantial, moderate and low) which councils are required to consider when undertaking their assessment. The criteria assess 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' and comprise:

¹⁵⁴ [2005] EWHC 428 (Admin) 8 CCLR 243 paras 35 - 39.

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.

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;¹⁵⁵ and
 - (b) to the carer.¹⁵⁶
- 5.3 If these services are provided to the disabled person, then they will be provided under the community care legislation or the Children Act 1989. 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'.¹⁵⁷ Whilst the Act makes no provision for services for carers, the outcome of such a carer's assessment will not

¹⁵⁵ 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 or under section 17 Children Act 1989 if the disabled person is under 18.

¹⁵⁶ 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 or under section 17 Children Act 1989 if the disabled person is under 18.

¹⁵⁷ Section 1(1) and s(2) Carers (Recognition and Services) Act 1995.

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 (or a Children Act 1989) service not a service provided under the Carers and Disabled Children Act 2000 (but see also para's 5.27 and 9.10 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 5.27 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.¹⁵⁸ The disabled person will of course be liable to pay the local authority's charges for the service.
- 5.10 The importance of timely respite care/short break services has been repeatedly highlighted by research, guidance and case law.¹⁵⁹ By way of example, guidance to the 1995 Act¹⁶⁰ 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'.¹⁶¹
- 5.11 Evidence of the importance of appropriate respite care is provided by virtue of its specific reference in Article 28(2) (c) of the UN Convention on the Rights of Persons with Disabilities which recognises the right of 'persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care'.
- 5.12 Not infrequently local authorities experience difficulties in addressing the specific respite care needs of disabled people and their carers. At law such needs (if assessed as 'eligible needs') must be met and if the authority fails to make a concerted effort to do this, it will constitute maladministration. Accordingly the Local Government Ombudsman has made such a finding in relation to a council's failure to put in place night time respite care (even if it was less than ideal).¹⁶² A further example is provided in a 2011 report¹⁶³ which concerned the failure of the council to provide respite care for a disabled deaf child. The council claimed that her needs were complex and it was difficult to find a respite carer who could both provide the care she needed and also had the necessary BSL skills. To this the ombudsman commented "There is no evidence that it considered the obvious and sensible expedient

¹⁵⁸ See for instance *R (Hughes) v Liverpool City Council* [2005] EWHC 428 (Admin) 8 CCLR 243 at para 33-34.

¹⁵⁹ See generally SCIE Resource Guide 14: *Having a break: good practice in short breaks for families who have children with complex health needs and disabilities* www.scie.org.uk

¹⁶⁰ 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.

¹⁶¹ D Challis et al, *Care Management and Health Care of Older People* (Canterbury 1995).

¹⁶² Complaint no 10 000 207; 10 004 245; & 11 000 195 against Southwark LBC, 22 May 2012 para 94.

¹⁶³ Complaint no 09 004 278 against Leeds City Council, 1st July 2011 (para 153 – 154).

of paying two people to work together, one to communicate with H and the other to provide for her care. Nor did it explore whether it could fund a carer to be trained in BSL.”

The range of respite care support

- 5.13 ‘Respite care’ is not phrase used by the law. In general terms, if a disabled person needs someone to sit with him/her, 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.
- 5.14 Respite / short break care can be facilitated, not merely by a sitting service under the 1970 Act or a residential placement under the 1948 Act, but by other diverse mechanisms. For example, the disabled person or their carer might be provided with a direct payment to enable them to arrange the break themselves (see para 5.35 below) or they might be provided with a joint holiday (also under s2 of the 1970 Act). Break services can be provided by the statutory or independent sectors. It will, therefore be maladministration if an authority fails to explore the potential for the independent sector to meet a need for respite care – particularly where that need is not being met by the statutory sector (for example because the disabled person / child in question has unusually challenging behaviour¹⁶⁴). The provision of respite / short break support should, therefore be based upon individual need and not the nature of the person’s disability or illness or the ease with which such support can be provided. It follows that the mere fact that a person has (for instance) challenging behaviour associated with their dementia, does not mean that the carer should not have the same right to respite support as carers of persons with other impairments.¹⁶⁵

Respite care & disabled children

- 5.15 The English Government’s report *Aiming High for Disabled Children: Better Support for Families* (2007)¹⁶⁶ highlighted the importance of short breaks in reducing the ‘high levels of stress’

¹⁶⁴ Ombudsman’s Report on a complaint against Complaint v Torfean CBC No. 1712/200600588 11 January 2008 at para 132

¹⁶⁵ In this regard, see Care Services Improvement Partnership (CSIP) (2008) *Creative models of short breaks (respite care) for people with dementia* at www.olderpeoplesmentalhealth.csip.org.uk/silo/files/short-breaks-pdf.pdf

¹⁶⁶ HM Treasury & the Department for Education and Skills (2007) accessible at http://www.hm-treasury.gov.uk/d/cyp_supportingfamilies290307.pdf at para 4.2.

present in many families with disabled children, stress that might otherwise 'result in family breakdown.' As a consequence £370 million was committed over the period 2008-11 to bolster the availability of short breaks support and this was extended in 2011 with an Early Intervention Grant for the period to 2015 period of over £800 million.

- 5.16 Legislative change has also accompanied the additional grant support. Section 25 Children and Young Persons Act 2008, amends the Children Act 1989¹⁶⁷ obliging social services authorities to 'assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring.' This duty, which came into effect in England in April 2011 and Wales in June 2012, has been the subject of detailed regulations¹⁶⁸ and guidance¹⁶⁹ in both nations, in very similar terms.
- 5.17 The Regulations require that in making available breaks from caring to assist parents and others who provide care for disabled children, local authorities must:
- ensure that, when making short break provision, they have regard to the needs of different types of carers, not just those who would be unable to continue to provide care without a break;
 - provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays; and
 - provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.
- 5.18 The guidance¹⁷⁰ amplifies the regulations by stressing that local authorities must ensure that:
- short breaks are reliable and regular to best meet families' needs;
 - local authorities should try to reach groups of parents who may be more difficult to engage;
 - parents are engaged in the design of local short breaks services;
 - short breaks can build on and be offered by universal service providers;

¹⁶⁷ By inserting a new paragraph into Schedule 2 para 6 (c).

¹⁶⁸ The Breaks for Carers of Disabled Children Regulations 2011 No. 707 and The Breaks for Carers of Disabled Children (Wales) Regulations 2012 No. 1674 (W.215)

¹⁶⁹ Department for Education (2011) Short Breaks for Carers of Disabled Children: Advice to local authorities and Welsh Government (2012) Best practice guidance - Breaks for carers of disabled children (Wales) Regulations 2012

¹⁷⁰ Page 1 of the Welsh guidance and page 5 of the English guidance.

- they are working in partnership with health services to understand the range of short breaks services in their area and to train the workforce;
- short breaks promote greater levels of confidence and competence for young people moving towards adult life;
- local authorities should ensure that those who use short breaks services have the chance to shape the development of those services; and
- they continue to develop their workforce in relation to short breaks services.

5.19 The strong advice in the both the English and Welsh guidance concerning the need for clear eligibility criteria for such services, follows the comments made by Black J in *R (JL) v Islington LBC* (2009) where she held that there was 'a pressing need' for such guidance (see para 3.36 above).

Withdrawing / not providing respite care.

5.20 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 Ombudsmen 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 court stated:¹⁷¹:

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.

5.21 In relation to waiting lists, the court and Ombudsman have been similarly forceful. The Ombudsman in a complaint report concerning Essex¹⁷² has stated:

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

¹⁷¹ *R v South Lanarkshire Council ex p MacGregor* (2000) 4 CCLR 188.

¹⁷² Complaint 00/B/00599 3rd September 2001; and see also *R v Islington LBC ex p Rixon* (1996)1 CCLR 119.

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.

- 5.22 An Ombudsman's complaint against North Yorkshire County Council¹⁷³ further 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.
- 5.23 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.
- 5.24 The Ombudsman was extremely critical of the local authority's failings: extracts from her lengthy report, include:

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. ...

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,

¹⁷³ Complaint 01/C/03521 against North Yorkshire 19th August 2002: [the names used are not the real names].

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.

Respite care and voucher schemes

5.25 Sections 3 and 7 Carers and Disabled Children Act 2000 provides for local authority social services departments to run short 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 while their usual carer is taking a break.

5.26 Regulations¹⁷⁴ 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 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.

¹⁷⁴ The Carers and Disabled Children (Vouchers) (England) Regulations 2003 SI No. 1216.

- 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

- 5.27 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 was the approach adopted by the former Commission for Social Care Inspection in England (now the Care Quality Commission), which required authorities to record the number of 'breaks services' that they had provided for carers.¹⁷⁵

Carers services

- 5.28 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

¹⁷⁵ CSCI PAF Guidance Book PAF C62 adopting the definition that applied in the Carers Grant Guidance.

can be anything that could ‘help the carer care for the person cared for’.¹⁷⁶

- 5.29 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.
- 5.30 The guidance accompanying the Carers Acts (outlined at para 3.17 – 3.20 above) 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 (SCIE)

- 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.

- 5.31 The range of services capable of being provided under section 2 Carers and Disabled Children Act 2000 is wide, given that anything that promotes a carer’s sense of personal well-being is likely to help them ‘care for the person cared for’. 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. The mere fact that there is only a power to provide does not mean that council’s can simply ignore the obligation – see para 5.42 below

¹⁷⁶ Section 2(2)(b) Carers and Disabled Children Act 2000.

- 5.32 In relation to the provision of carers' services, the practice guidance accompanying the 2000 Act¹⁷⁷ states (amongst other things):

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.

- 5.33 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'.
- 5.34 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 service¹⁷⁸ 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.¹⁷⁹ Notwithstanding this finding, it remains the case that many local authorities continue to have such unlawful policies.

Direct payments

- 5.35 Section 57 Health and Social Care Act 2001 enables social services departments to give carers direct payments instead of providing them with a 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

¹⁷⁷ Para 80; the Welsh guidance contains no equivalent statement.

¹⁷⁸ Under s2(1)(a) Chronically Sick and Disabled Persons Act 1970 – ie 'practical assistance in the home'.

¹⁷⁹ Complaint No. 01/C/17519 against Salford CC 11.12.03

direct payment – with which he or she then undertakes to purchase the service assessed as being required.

- 5.36 Guidance on the direct payments scheme has been issued in both England¹⁸⁰ and Wales¹⁸¹ 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.
- 5.37 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 – or the local authority is able to pay it to a third party (for instance the carer) using its powers under s146 Health & Social Care Act 2008 – see para 5.41 below.
- 5.38 Where a disabled person has been assessed as needing a service, then in general there is a duty to make the provision by way of a direct payment if so requested. In this context the Ombudsman has held it be maladministration for a local authority:
- to require a parent carer to give reasons why he wanted a direct payment in lieu of a service, and for the authority to state 'that direct payments would not be paid for childcare and that childcare was the responsibility of the parents, whether or not children have a disability'¹⁸² (and see also para 4.67 above);
 - to have a policy of refusing direct payments for certain services – such as short (overnight) breaks.¹⁸³
- 5.39 The relevant social security regulations require 'any payment' made under the direct payments legislation to be disregarded for benefits purposes.¹⁸⁴ This does not, however, apply to carers who are paid using these payments – since the

¹⁸⁰ Department of Health (2009) *Guidance on direct payments for community care, services for carers and children's services England 2009* accessible at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840

¹⁸¹ Welsh Government (2011) *Direct Payments Guidance Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Guidance 2011*.

¹⁸² Public Service Ombudsman (Wales) Complaint No. B2004/0707/S/370 against Swansea City Council 22 February 2007 see in particular paras 78, 133 & 137.

¹⁸³ Complaint no 08 005 202 against Kent CC, 18 May 2009, para 39 – in this case the council had refused on the grounds that it was able to provide these 'in house'.

¹⁸⁴ Income Support (General) Regulations 1987 SI No 1967 Sch 9 para 58; Jobseeker's Allowance Regulations 1996 SI No 207 Sch 7 para 56; Housing Benefit Regulations 2006 SI No 213 Sch 5 para 57.

disregard does not apply to 'earnings'.¹⁸⁵ In such cases a carer could however still benefit from the Income support earnings disregard (though modest) and it has also been suggested that, in certain cases the problem could be avoided by the local authority making the direct payment to the carer under the carers legislation.¹⁸⁶

- 5.40 Disabled people who are receiving direct payments are entitled to use their payments to employ a family member. The relevant regulations, however, restrict their ability to employ a partner / spouse or a family member who lives in the same household, to situations where the local authority is satisfied that this 'is necessary to meet satisfactorily' the disabled person's needs.¹⁸⁷ This is a relatively low threshold test albeit that some authorities maintain legally mistaken policies permitting such payments, only in 'exceptional circumstances'. Where a direct payment is being used to pay a carer, this has the potential to undermine the rights of the carer to Carer's Allowance and possibly to a carer's assessment – since the assessment right is predicated on 'the care in question' not being provided by virtue of contract of employment'.¹⁸⁸ Whether the right to an assessment is lost by such an arrangement will depend on a careful appraisal of the facts in each case – particularly the amount of care and the amount of the direct payment. Thus, for example, if taking into account the amount of paid care, the amount of the unpaid care remains substantial, the entitlement to a carer's assessment would endure. In such cases, it is probably best to approach the question from the perspective of 'good practice' rather than straining on the minutiae of legal interpretation. The local authority has power to provide support under other legislation (for example, s2 Local Government Act 2000) and so the key question should be – "What sort of support would good social work practice suggest should be provided in this case?"

Direct payments to carers for disabled people's services

- 5.41 Although a carer can be the recipient of a direct payment for services needed by a disabled child, once a disabled person is 18, the direct payments for their support needs (for instance a sitting service) must in general be paid to that person. This requirement has caused difficulties where the disabled adult lacks the mental capacity to agree to the payment – due for instance to dementia or a profound learning disability. To address this difficulty, s146 Health & Social Care Act 2008

¹⁸⁵ See *Casewell v. Secretary of State for work and Pensions* [2008] EWCA Civ 524.

¹⁸⁶ See commentary in the Journal of Community Care law Issue 49 June 2008.

¹⁸⁷ The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 SI No. 1887, regulation 11 and regulation 12 Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2011 SI 831 (W.125)..

¹⁸⁸ s1(3)(a) Carers (Recognition & Services) Act 1995 and s1(3)(a) Carers & Disabled Children Act 2000.

enables local authorities to make direct payments to a third party (for example, a carer) where the disabled person lacks the necessary mental capacity. Detailed guidance on the operation of the s146 procedures has been published in England¹⁸⁹ and Wales in very similar terms.¹⁹⁰ In general a local authority has the power to pay direct payments to someone on behalf of a disabled persons (who lacks the necessary mental capacity to consent to such a payment) where that third party agrees to the arrangement – although if the disabled person has appointed a Lasting Power of Attorney (LPA) or has a Court of Protection appointed ‘deputy’ then slightly different procedures exit, albeit that there is still a local authority power to make such a payment.

Power and not a duty

5.42 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 most situations (and in this context, the comments of the CSCI cited at para 4.88 above are important). However, the mere fact that the obligation is discretionary rather than mandatory 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 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 court’s 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’.¹⁹¹

¹⁸⁹ Department of Health (2009) *Guidance on direct payments for community care, services for carers and children’s services England 2009* accessible at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840

¹⁹⁰ Welsh Government (2011) *Direct Payments Guidance Community Care, Services for Carers and Children’s Services (Direct Payments) (Wales) Guidance 2011*.

¹⁹¹ *R v Warwickshire County Council ex p Collymore* [1995] ELR 217, at 224

6. The rights of disabled people – an overview

Community Care Assessments

6.1 If a carer is seeking assistance from the social services department, the first response 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 described briefly 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 personnel 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 (formerly known as the Fair Access to Care Services (FACS) Guidance) is '*Prioritising need in the context of Putting People First*' (2010),¹⁹² whereas the key guidance in Wales is known as the Unified and Fair System for Assessing and Managing Care' (UFSAMC) 2002: these are similar. In addition there is a plethora of other guidance – which is specific to certain user groups, for instance:

Older People

¹⁹² But now replaced by Department of Health (2010) guidance entitled *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010* para 54 and in Wales in the Welsh Assembly Government's (2002) guidance *Creating a Unified and Fair System for Assessing and Managing Care* at para 5.16

The Single Assessment Process Guidance¹⁹³.

Mental health service users

The Care Programme Approach¹⁹⁴ (2008).

People with learning disabilities

Valuing people guidance (2001)¹⁹⁵.

- 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*.¹⁹⁶

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 carers' assessment. The views of the local health service must also be sought¹⁹⁷ as well as enquiries made about the suitability of his housing¹⁹⁸ and alternatives (for instance sheltered housing etc).

¹⁹³ Accessible at www.dh.gov.uk/assetRoot/04/01/22/89/04012289.pdf; in Wales the *Unified & Fair System for Assessing & Managing Care* (UFSAMC) 2002

¹⁹⁴ Department of Health (2008) *Refocusing the Care Programme Approach* Department of Health March 2008; Welsh Assembly Government (2001) *Adult Mental Health Services in Wales: Equity, Empowerment, Effectiveness, Efficiency. A Strategy Document*, 2001.

¹⁹⁵ Valuing people: a new strategy for learning disability for the 21st century (2001). Valuing people: implementation policy guidance LAC (2001)23 – to be read in conjunction with the revised Department of Health policy document *Updated Valuing People Now: a new three-year strategy for learning disabilities* (2010).

¹⁹⁶ The English guidance (2000) is accessible at www.doh.gov.uk/scg/cin.htm and the Welsh (2001) at www.wales.gov.uk/subchildren/content/framework-m/framework-m.pdf

¹⁹⁷ Section 47(3) National Health Service and Community Care Act 1990.

¹⁹⁸ Section 47(3) National Health Service and Community Care Act 1990.

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 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. In assessing Albert's needs' (and the potential consequences to him of not providing services to meet his needs) the care provided by his wife must be ignored (see para 4.43 above).

Stage 3

Having undertaken a carers 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. In certain situations the disabled people are entitled to use their direct payments to pay a family member or partner to provide their care – and this question (and the entitlement of carers to direct payments in their own right) is considered at para 5.35 above.

6.5 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 at the impact her disability may be having on her parents and her brother. This part of the assessment might find that Rupee's mother wished to return to work, but was unable to do so due to the exceptional demands made by Rupee, and that Rupee's brother was providing her with large amounts of care. The responsibility of the local authority to promote the mother's wish to work is considered at para 11.4 below – as is the question of their responsibilities towards 'young carers' (see section 10 below).

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 are such that on occasions she needs to be apart 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 (for instance with temporary foster parents) or that someone comes to her home and sits with her, whilst other family members leave for a short time on their own. In assessing whether this support should be made available, the social services department will again have regard to the consequences – what would happen – if no help was provided as discussed above.

Stage 3

The final stage (as with the community care assessment example above) requires the preparation of a '*care plan*' which explains what services the social services department will provide in order to meet the needs of Rupee and her family. This might, for instance spell out when, where and how often respite care support will be provided, what other general assistance will be made available, detail adaptations or equipment required in the home – and so on.

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. In Wales the Carers Strategies (Wales) Measure 2010 obliges Local Health Boards to develop information and support strategies and this requirement is considered separately at para 4.26 above.
- 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 that (at para 30)
- ... 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 The English Government continues to stress the importance of GP's identifying carers and referring them to support services – for example in 2007 it was stated that:¹⁹⁹
- we want GPs ... to identify those of their patients who are carers—as GPs are frequently the health care professionals whom carers have the most contact with and confidence in — and then, having identified them, make sure that they get signposted to whatever services they need to support them to fulfil their caring responsibilities.
- 7.4 The NHS Constitution (2010)²⁰⁰ pledges to 'work in partnership with you, your family carers and representatives' and lists

¹⁹⁹ The Parliamentary Under-Secretary of State for Health (Mr. Ivan Lewis), House of Commons Hansard, 13 Mar 2007 at Column 146.

²⁰⁰ Department of Health (2010) The National Health Service Constitution at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_11361

seven key principles to 'guide the NHS in all it does', of which Principle Four is:

NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.

- 7.5 The 2008 English Carers Strategy²⁰¹ committed £150 million in the period to 2011 to enable Primary Care Trusts (PCTs) to provide emergency and planned respite breaks for carers.²⁰² In addition the strategy requires that PCTs (working in collaboration with the relevant councils) 'publish joint plans on how their combined funding will support breaks for carers, including short breaks, in a personalised way'.
- 7.6 Notwithstanding these new initiatives the perception remains of a general failure by the NHS to address the needs of carers. This concern is evidenced by periodic statements reminding PCTs and other health providers of Government policy guidance regarding the 'critical role carers play'²⁰³ and of concern about the 'lack of recognition' within the NHS of the 'vital role' played by carers and of the need for NHS organisations to 'actively [work] in partnership with social services to consult, inform and support carers.'²⁰⁴
- 7.7 In June 2004 the Department of Health issued service delivery targets to NHS bodies²⁰⁵ that required (amongst other things) that NHS staff treat patients and carers with dignity and respect (C13) and to take into account their views when designing, planning, delivering and improving health care services (C17). In addition, the Combined Policy Guidance under the 2000 and 2004 Acts (para 34) required 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.
- 7.8 In an attempt to give legislative force to these routine 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

²⁰¹ Department of Health (2008) *Carers at the heart of 21st-century families and communities* at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345

²⁰² Ibid para 3.11 and see Department of Health (2008) *The NHS in England: The operating framework for 2009/10* para 37.

²⁰³ Minister of Health, HC Deb 6 May 2003 c663W.

²⁰⁴ Department of Health, *Chief Executive's Bulletin*, 28 March to 3 April 2003, para 8.

²⁰⁵ The National Standards, Local Action Health and Social Care Standards and Planning Framework 2005/06–2007/08 accessible at www.dh.gov.uk/assetRoot/04/08/60/58/04086058.pdf

and welfare of carers. Although the first provision is present in the final Act (albeit in less robust form – see para 7.15 below) the second is not. Dr 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.²⁰⁶ Unfortunately the Government then changed its mind. The Minister apologised for ‘having inadvertently misled Members’, and stated:

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 alternatives²⁰⁷

7.9 To date this undertaking has not been discharged. In June 2004 the then Government stated that it was still considering how best to take the commitment forward, but that it would require:

the local NHS to demonstrate to their strategic health authorities that they are effectively taking account of the needs of carers in their planning processes. If strategic health authorities are not satisfied that that is the case or if the Department of Health has specific examples of how the process is not working, we will intervene. I can reassure my noble friend about that²⁰⁸

7.10 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.]

²⁰⁶ Under what was s28 Health Act 1999: 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].

²⁰⁷ The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): House of Commons Hansard 14 May 2004 : Column 586.

²⁰⁸ The Parliamentary Under-Secretary of State, Department of Health (Lord Warner): stated “House of Lords Hansard 25 June 2004 Column 1493.

The NHS duty to cooperate

Background

- 7.11 Research by Carers UK, *Ignored and Invisible*²⁰⁹, found that carers' top priority was health and social services working together. In Carers UK's opinion, 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.
- 7.12 This view is strongly endorsed by the findings of a pilot study by Department of Health,²¹⁰ involving 25 'Demonstrator Sites' in the period 2009 – 2011, which suggested that if the NHS were to concentrate on improving its involvement and engagement with carers and other statutory and third sector agencies, that this would have very many benefits, not least preventing carer burn-out / health deterioration and sustaining carers in their caring role. The report considered that for the 'relatively modest cost' in developing such arrangements, programmes of this type could be justified as financially sustainable.
- 7.13 The House of Commons Research Paper²¹¹ that accompanied the Carers (Equal Opportunities) Bill stated that despite the good intentions of the *National Strategy*²¹² it appeared that the advice concerning health joint working was not being applied and cited the Carers UK Report *Missed Opportunities*²¹³ 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'.
- 7.14 In Wales, the Carers Strategies (Wales) Measure 2010 places great emphasis on joint working between Local Health Boards and their partner agencies – but this is largely limited to the preparation of their information and support strategies, advising for example (para 3.6):

The Strategy must be developed and operate in an environment based on partnership working, team-working, information-sharing and service integration across all levels of the NHS. It must function in partnership with Carers, patients, NHS staff, local

²⁰⁹ *Ignored and Invisible*, Carers UK, 2001

²¹⁰ University of Leeds (2011) 'New Approaches to Supporting Carers' Health and Well-Being: Evidence from The National Carers' Strategy Demonstrator Sites Programme' at <http://www.sociology.leeds.ac.uk/assets/files/research/circle/151111-circle-newapproaches-report-summary.pdf>

²¹¹ Carers (Equal Opportunities) Bill: Research Paper 04/13 by Tim Jarrett & Adam Mellows-Facer 3/2/04 accessible at www.parliament.uk/commons/lib/research/rp2004/rp04-013.pdf

²¹² Accessible at www.carers.gov.uk/pdfs/Care.pdf

²¹³ Carers UK, *Missed Opportunities: the impact of new rights for carers*, June 2003.

authorities, the Third sector, the private sector and other relevant groups. ... The success of an effective Strategy will depend greatly on the quality of these partnerships as well as effective communication and joint working between all partners, including Carers and the Third sector. It will also depend on open and robust accountability within statutory and independent agencies

7.15 The Measure is considered separately at para 4.26 above.

The general duty to cooperate

7.16 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.

7.17 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 'gasp[ed] the nettle' and secured the provision, before entering into protracted negotiations with the NHS on liability for the care costs.²¹⁴

The duty to cooperate under the 2004 Act

7.18 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 body²¹⁵ 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

²¹⁴ Complaint 96/C/3868 against Calderdale MBC and see also the Report by the Public Services Ombudsman for Wales and the Health Service Ombudsman for England of an investigation of a complaint about the Welsh Assembly Government (Health Commission Wales) Cardiff and Vale NHS Trust and Plymouth Teaching Primary Care Trust, Third Report, Session 2008-2009 HC 858 (TSO, 2009).

²¹⁵ 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'.

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.

7.19 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.

7.20 Research evidence produced by the Patients Association²¹⁶ provides an example of the problems experienced by carers as a consequence of NHS failures in this respect – suggesting that approximately 2½ million people in the UK have had to take time off work to arrange short-term post-hospital care for older relatives.

7.21 During the passage of the Bill the government described the expected impact of this provision²¹⁷:

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

²¹⁶ *Who Will Look After Mum?* June 2005 accessible at www.wpa.org.uk/downloads/parentcare_release_140605.pdf

²¹⁷ The Parliamentary Under-Secretary of State for Health (Dr. Stephen Ladyman): House of Commons Hansard Standing Committee C Wednesday 10 March 2004 column 22.

put their case, usually a strong one, about the benefits offered in individual circumstances.

- 7.22 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'.
- 7.23 A department of health advice / review note concerning wheelchair provision²¹⁸ gives as an example of the use of the section 3 powers under the Carers (Equal Opportunities) Act 2004 – a 'social services might request that the NHS provide a certain type of wheelchair (perhaps a bit more expensive than usual) in order not only to meet the needs of the disabled person, but also to make life easier for the carer'.

Joint working in England & the NHS Operating Framework

- 7.24 The NHS Operating Framework is the mechanism by which the Department of Health spells out what it requires – in terms of planning, performance and finance – from NHS bodies in England. The operating framework for 2012-13²¹⁹ places (at para 2.11) an important emphasis on meeting the needs of carers, stating:

Carers

2.11 Carers play a vital role in our system and must receive help and support from local organisations. Following a joint assessment of local needs, which should be published with plans, PCT clusters need to agree policies, plans and budgets with local authorities and voluntary groups to support carers, where possible using direct payments or personal budgets. For 2012/13 this means plans should be in line with the Carers Strategy and:

- be explicitly agreed and signed off by both local authorities and PCT clusters;
- identify the financial contribution made to support carers by both local authorities and PCT clusters and that any transfer of funds from the NHS to local authorities is through a section 256 agreement;
- identify how much of the total is being spent on carers' breaks;
- identify an indicative number of breaks that should be available within that funding; and

²¹⁸ Department of Health (2006) *Out and about Wheelchairs as part of a whole-systems approach to independence* Care Services Improvement Partnership (October 2006) at page 30.

²¹⁹ Department of Health (2011) *The Operating Framework for the NHS in England 2012/13* at www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf

- be published on the PCT or PCT cluster's website by 30 September 2012 at the latest.”

Hospital discharge

General rights

- 7.25 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 handled badly.
- 7.26 Many carers express dissatisfaction about the way hospital discharge takes place. There is the perception that hospital authorities accelerate discharges, when there is known to be a carer at home, without pausing to assess the impact that the discharge may have on that person. As the English hospital discharge guidance²²⁰ acknowledges, the evidence suggests that ‘there is still much to do to improve the experience of planning for, and moving from, hospital care’. The guidance then cites research (2008) that found:
- For family carers, the discharge process was often very stressful and at points they felt a sense of both powerlessness and of having to fight to achieve what they considered would be best for their relatives.²²¹
- 7.27 ‘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.
- 7.28 Although patients have, in general,²²² 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.
- 7.29 The relationship between the NHS and social services in the discharge process is shaped by central government guidance, and additionally (in England²²³) by statute – the Community

²²⁰ *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care* (2010) Department of Health at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113950 p27.

²²¹ Hubbard et al (2008) *Reimbursement in practice: The last piece of the jigsaw?* University of Stirling, University of Leeds, King's College London.

²²² 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,

²²³ There is no present intention to bring it into force in Wales.

Care (Delayed Discharge etc.) Act 2003. The Act's impact on carers is considered separately below (see para 7.37).

- 7.30 The key general guidance on discharge arrangements in England is known as *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care* (2010)²²⁴ which supersedes (rather than repeals²²⁵) the more extensive 2003 guidance *Discharge from hospital: pathway, process and practice*.²²⁶ The relevant guidance in Wales is *Hospital Discharge Guidance* (2005)²²⁷ and *Passing the Baton - A Practical Guide to Effective Discharge Planning* (2008)²²⁸. The English Guidance is cited in the subsequent paragraphs (being referred to as the 2003 or 2010 guidance (as the case may be). 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. Advice concerning hospital discharge in the Carers Strategies (Wales) Measure 2010 is considered at para 7.36 below.

Patient and carer involvement

- 7.31 The 2003 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'²²⁹. 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'. The 2010 guidance stresses (p.29) that 'carers should be involved in decision-making from the beginning' and that those involved in coordinating a discharge should 'not assume that a carer will necessarily be able or willing to continue in a caring role'.
- 7.32 Both the 2003 and the 2010 guidance acknowledge that carers have often considered themselves marginalised by discharge arrangements, particularly with patients being sent home too early leaving their carers to cope with unacceptable caring

²²⁴ Department of Health at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113950

²²⁵ The 2010 *Ready to go?* guidance cites the 2003 *Pathways* guidance on a number of occasions.

²²⁶ Department of health, accessible at: www.dh.gov.uk/assetRoot/04/11/65/25/04116525.pdf

²²⁷ National Assembly for Wales (2005) 'Hospital Discharge Planning Guidance' NAFWC 17/2005.

²²⁸ At www.nliah.com/Portal/microsites/CMSPageDisplay.aspx?CMSPageID=364.

²²⁹ Para 1.2 and at para 4.5.1 provides a detailed 'carer's checklist' of relevant factors to be considered.

situations.²³⁰ 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’ (see para 4.3, 2003 guidance).

- 7.33 The 2003 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

- 7.34 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)²³¹. The Ombudsman has also criticised as inadequate the provision of

²³⁰ 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.

²³¹ Fifth Report for session 1995–96, *Investigations of Complaints about Long-Term NHS Care*, HMSO, complaint E.685/94-95

general brochures to patients and situations where staff provided patients and their carers with only limited advice on their possible options.²³²

- 7.35 The 2003 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).

Wales specific advice

- 7.36 In Wales the 2005 Hospital Discharge Guidance²³³ places considerable emphasis on 'patients and their families/carers are fully engaged at all stages in the discharge process'. The guidance²³⁴ accompanying the Carers Strategies (Wales) Measure 2010 also stresses the importance carer involvement – and of an awareness of this point to be included in staff training (para 4.13). At para 3.23 it advises that 'Information on hospital discharge and transfers of care should include as a minimum:

- information about the support and follow up available on discharge for the carer and the patient; including the practicalities of the process, timing, medication rights to assessment etc;
- personal and often sensitive information relating to the individual patient about the diagnosis, prognosis and treatment and management both in hospital and afterwards; and
- information that enables the Carers to perform their future role safely and with the necessary skills and knowledge to make informed choices about capacity to meet the needs of the patient who becomes the person cared for both on discharge and over time. **This information needs to be provided to assist the carer to decide if they want to be a carer and to enable them to choose the level of responsibility they wish to take** (emphasis as in the guidance)

Community Care (Delayed Discharge etc.) Act 2003

- 7.37 The 2003 Act is designed to encourage social services to speed up the discharge of patients who no longer require care in an acute hospital.²³⁵ It enables a hospital to serve on the relevant social services department an 'assessment' notice

²³² The above cited NHS Ombudsman's Report, complaint E.672/94-95.

²³³ National Assembly for Wales (2005) 'Hospital Discharge Planning Guidance' NAFWC 17/2005.

²³⁴ Welsh Government (2012) Carers Strategies (Wales) Measure 2010: Guidance issued to Local Health Boards and Local Authorities.

²³⁵ Maternity care, mental health care, palliative care, intermediate care and care provided for recuperation or rehabilitation are excluded from the definition of acute care.

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.²³⁶

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.

- 7.38 As with general guidance on hospital discharge, that which accompanies the delayed discharge scheme²³⁷ 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.²³⁸
- 7.39 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 decisions 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 package²³⁹. At the end of the day, 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.²⁴⁰

²³⁶ HSC 2003/009 LAC (2003) 21 para 47.

²³⁷ See for example, 'Frequently asked questions on reimbursement' accessible at www.dh.gov.uk/assetRoot/04/07/19/26/04071926.pdf

²³⁸ 'Frequently asked questions ...' as above Q. 28

²³⁹ 'Frequently asked questions ...' as above Q. 29.

²⁴⁰ 'Frequently asked questions ...' as above Q. 31.

NHS Continuing Healthcare

- 7.40 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 Healthcare' support.²⁴¹
- 7.41 In the leading case on this question, *R v. North and East Devon health authority ex p Coughlan*²⁴², the Court of Appeal held that in general social services authorities had no responsibility for people who were entitled to NHS Continuing Healthcare 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.²⁴³
- 7.42 The Department of Health in England and the Welsh Assembly Government have put the question beyond doubt in their National Frameworks for NHS Continuing Healthcare²⁴⁴ which state in terms (at para 45 and 4.7 respectively) that carers do not lose their entitlement to an assessment under the Carers legislation when the person for whom they care is entitled to NHS Continuing Healthcare.

²⁴¹ For a detailed review of this area of law see Clements, L and Thompson P (2011) *Community Care and the Law* 5th edition Legal Action Group, London chapter 14.

²⁴² *R v. North and East Devon health authority ex p Coughlan* [2000] 2 WLR 62.

²⁴³ For a detailed analysis of the intricate nature of the law in this field, see L Clements and P Bowen, *NHS Continuing Care and independent living* (2007) 10 CCLR 343–351.

²⁴⁴ Department of Health (2009) *The national framework for NHS continuing healthcare and NHS-funded nursing care - July 2009 (revised)* at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_10316 and the Welsh Assembly Government (2010) *Continuing NHS Healthcare: The National Framework for Implementation in Wales Circular: 015/2010* at <http://wales.gov.uk/docs/dhss/publications/100614chcframeworken.pdf>

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 carers allowance (and process for claiming this allowance) can be accessed at the 'Directgov' information site at www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Caringforsomeone/DG_10018705

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 2000.²⁴⁵ 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 This guide does not address the charging rules for disabled people's services.²⁴⁶ These rules do however impact on carers and in this context, the following two issues are of particular relevance:

Separate treatment of carers & disabled people's income

8.4 The charging rules for adult disabled peoples' services stress that it is only the disabled person's financial circumstances that

²⁴⁵ Section 8 Carers and Disabled Children Act 2000.

²⁴⁶ For an overview of these charges – see the Age UK guidance leaflets on paying for such care at www.ageuk.org.uk/publications/home-and-care-publications/ or the equivalent Disability Law Service leaflets at www.dls.org.uk/advice/Factsheet/factsheets_download.html and for a detailed review of the charging rules, see Clements L, and Thompson P (2011) *Community Care and the Law*, Legal Action Group, London 5th edition, chapters 8 and 10.

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 adults for residential care accommodation, the 'Charging for Residential Accommodation Guide' (CRAG)²⁴⁷ states (at para 4.001):

Under the National Assistance Act 1948, the local authority has no power to assess a couple, or civil partners, according to their joint resources. Each person entering residential care should be assessed according to their individual means.

- 8.6 The same rules apply in relation to non-residential care services for adults (for instance home help or day centre services). Thus the relevant guidance 'Fairer Charging Policies for Home Care and other non-residential Social Services'²⁴⁸ 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 carer²⁴⁹.

- 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.

²⁴⁷ The version of CRAG applying in England can be accessed at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114330 and that in Wales can be accessed at <http://wales.gov.uk/topics/health/publications/socialcare/guidance1/CRAG10/?lang=en>

²⁴⁸ The English Guidance can be accessed at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4117930 and the Welsh at www.wales.gov.uk/subisocialpolicy/content/consultations/charging/guidance-e.doc

²⁴⁹ Para 81 of the English guidance and para 69 in Wales.

Liabile relative rules

8.8 Prior to April 2009 local authorities were able to seek a contribution towards a disabled persons care costs from their spouse. The rule no longer exists, being repealed by s147 Health and Social Care Act 2008.

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 purposes. 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 partner²⁵⁰ (except where the resident is estranged or divorced from the former partner – unless a lone parent); or
 - a relative²⁵¹ of the resident or member of his or her family (ie, another person for whom the resident is treated as responsible) who:
 - is aged 60 or over, or
 - is aged under 18 and is a child whom the resident is liable to maintain, or
 - is incapacitated²⁵².

²⁵⁰ 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.

²⁵¹ '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 7.007). The relevant point here is that this is an *inclusive* definition rather than an *exclusive* one.

²⁵² 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 7.009).

- 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.²⁵³ Paragraph 7.011 of CRAG suggests that:

LAs 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 do do this – especially if the carer has provided care for a number of years.

Charging and disabled children's services

- 8.11 The Children Act 1989 permits local authorities to make charges for services provided for disabled children²⁵⁴ and to include their parents' means in arriving at such charges. As with adults, this guide does not address the charging rules in detail,²⁵⁵ but the following points are of general relevance.
- 8.12 Firstly most local authorities have not charged for such support services in the past and all such authorities should be mindful of General Comment No. 9 of the UN Committee on the Rights of the Child (the UK having ratified the UN Convention on the Rights of the Child (CRC)). The Committee, having stressed the importance of article 23 CRC (that a child with disability and her or his parents and/or others caring for the child receive 'special care and assistance') that this support should be 'free

²⁵³ Regulations Sch 4 para 18.

²⁵⁴ Section 29 Children Act 1989 in relation to community based services and CA 1989 Sch 2 Part III in relation to residential care placements.

²⁵⁵ For a detailed review of the charging rules, see Clements L, and Thompson P (2011) *Community Care and the Law*, Legal Action Group, London 5th edition, chapter 23.

of charge whenever possible'. In deciding what is 'possible' (since the CRC has interpretative relevance in the UK) it needs to be born in mind that the CRC has been signed by 193 states and of these the UK is currently the 6th richest.

8.13 Secondly in relation to any charges that might be levied, s29 Children Act 1989 provides that:

- no person can be charged while in receipt of income support, or of any element of child tax credit (other than the family element) or working tax credit or of an income-based jobseeker's allowance or of income-related employment and support allowance; and
- that where the authority is satisfied that a person's means are insufficient for it to be reasonably practicable for them to pay the charge, the authority cannot require them to pay more than he or she can reasonably be expected to pay.

Carers Grant

8.14 As part of the 1999 National Strategy for Carers²⁵⁶ 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 Wales²⁵⁷. In England the underlying purpose of the Grant has been explained as to²⁵⁸:

- further develop innovative and high quality carers services in response to local needs.
- develop pragmatic, outcome focused approaches to the carers 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

²⁵⁶ www.carers.gov.uk/pdfs/Care.pdf

²⁵⁷ See www.wales.gov.uk/subicarersnew/information-e.htm

²⁵⁸ Carers Grant Guidance 2004 / 05, para 5, accessible at www.carers.gov.uk/carersgrant04_05.PDF

- 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.

8.15 Research suggests that the grant has been effective in promoting flexible breaks for carers²⁵⁹ although in April 2004 and is now technically embedded in local authority core spending²⁶⁰ in England albeit that local authorities will continue to be monitored by the Care Quality Commission on the extent to which they are providing such respite care services and will need to demonstrate progress against the newly refreshed National Carers Strategy.

²⁵⁹ 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)

²⁶⁰ 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

9. Carer / service user conflict

General principles

9.1 The Circular that accompanies the English Community Care Directions 2004, (LAC (2004)24)²⁶¹ 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:

²⁶¹ Accessible at www.dh.gov.uk/assetRoot/04/08/83/70/04088370.pdf

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 carers assessment coincide with a disabled persons 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 carers 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 local authority's eligibility criteria for services (see para 6.4, stage 2 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 follows that 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 Act does not require a disabled person to be 'eligible for services' or 'receiving services'. A few authorities have suggested that carers can only get support if the disabled person meets their 'eligibility criteria' for services – but this again is mistaken since 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 and 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

3.30) the Local Ombudsman has been highly critical of a local authority that refused to undertake a carer's assessment in such a situation.²⁶²

Where a disabled person refuses community care services

9.7 Not infrequently a disabled person may refuse 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 difficult situations can only be resolved by skilled and sustained social work. The courts have repeatedly held that social services departments cannot take a simple refusal of help at face value. They should continue to try and engage with the person.²⁶³

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?

²⁶² Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004.

²⁶³ See for instance *R v Kensington & Chelsea RLBC ex p Kujtim* (1999) 2 CCLR 340 at 354! and *R (Patrick) v. Newham LBC* (2000) 4 CCLR 48.

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 report²⁶⁴ 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 ...²⁶⁵

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 by reference to the following example:

²⁶⁴ Complaint No 03/C/16371 against Stockton-on-Tees Borough Council 18 January 2005 paragraph 13.

²⁶⁵ *Valuing People*, paragraph 5.7 and see also Circular HSC 2001/016: LAC(2001)23 paragraph s 37 & 38.

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

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

a) Elsie is eligible for community care support. If Elsie agrees to be assessed by social services, then a cleaning and laundry service could be provided as a **community care service** and delivered to her. Elsie would be the person financially assessed for any charges.

b) If Elsie refuses to be assessed by social services (although she would be eligible for community care services) Jim could ask for a carers' assessment. The local council could agree to provide, as a carer's service, a cleaning and laundry service at Elsie's house. The local council would need to be satisfied that Elsie is prepared to tolerate the visits from these services. It turns out that so long as they don't bother her, Elsie will tolerate them. Social services arrange to pick the laundry up when Jim is at Elsie's home. This is a **carer's service provided for the carer (Jim), delivered to the cared for person (Elsie)**. Jim would be liable for any charge as the service is provided to help him in his caring role. Jim and the care manager hope that Elsie will get used to people other than Jim coming round and may subsequently change her mind about being assessed and helped by social services.

c) If Jim decides that the easiest way for him to cope with all this extra laundry is for him to have a new washing machine installed at his own home, he could then discuss with the care manager the provision of a direct payment so that he can buy one. This would then be a **carers' service provided for the carer (Jim), delivered to the carer (Jim)**. Jim would again be the person financially assessed in relation to any charges.

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 Act²⁶⁶ 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

²⁶⁶ Para 25, this section does not appear in the Welsh guidance.

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 Regulations²⁶⁷ 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 (ie 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 Regulations²⁶⁸ 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

²⁶⁷ Regulation 2(1) of the Carers (Services) and Direct Payments (Amendment) (England) Regulations 2001SI No. 441 and in Wales The Carers (Services) and Direct Payments (Amendment) (Wales) Regulations 2001 SI No. 2186 (W. 150).

²⁶⁸ As above, Regulation 2(2) and see also para 28 of the 2001 policy guidance (para 2.3 of the Welsh Guidance).

10. Young carers

- 10.1 Carers who are under the age of 18 are generally referred to as 'young carers'. Whilst the 2001 census indicated that there were at least 175,000 young carers in the UK, research conducted for the BBC in 2010 suggested that there may in fact be four times as many – some 700,000 young carers.²⁶⁹
- 10.2 The Equality and Human Rights Commission's (EHRC) in its 2010 Equality Review,²⁷⁰ when stressing the importance of addressing the inequality experienced by young carers noted that a disproportionate number were from certain ethnic minority backgrounds (including Bangladeshi, Black African and Black Caribbean and Pakistani).
- 10.3 The EHRC's emphasis on considering the position of young carers from a human rights perspective is important. As Lord Kerr's has observed:²⁷¹
- It is a universal theme of the various international and domestic instruments ... that, in reaching decisions that will affect a child, a primacy of importance must be accorded to his or her best interests. ... It is a factor ... that must rank higher than any other. It is not merely one consideration that weighs in the balance alongside other competing factors. Where the best interests of the child clearly favour a certain course, that course should be followed unless countervailing reasons of considerable force displace them.
- 10.4 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 carers assessment under the 1995 Act, young carers' may also be entitled to services in their own right, under the Children Act 1989. The fact that there is an overlapping obligation does not mean that one or other Act can be ignored: they are both duties that stem from primary legislation, and the Ombudsman has held it to be maladministration not to undertake a separate carers assessment in such cases.²⁷² The binding Policy

²⁶⁹ D Howard (2010) *Cameron warns on child carer cuts* 16 November 2010 at www.bbc.co.uk/news/education-11757907

²⁷⁰ Equality and Human Rights Commission (2010) *How fair is Britain?* Executive Summary p33 at www.equalityhumanrights.com/key-projects/triennial-review/

²⁷¹ *ZH v Secretary of State for the Home Department* [2011] UKSC 4.

²⁷² See for example, complaint No 07B 04696 and 07B 10996 against LB Croydon 16th September 2009.

Guidance to the Children Act 1989 (the *Framework for the Assessment of Children in Need and their Families*²⁷³) expresses the duty in the following terms (at para 3.63):

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.

- 10.5 The importance of the young carer obligation under the 1995 Act stems in part from the failure of some Adult Services Departments to identify and properly support 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 10.10 and 11.14 below) and this has been reinforced by the binding English policy guidance, '*Prioritising need in the context of Putting People First*' (2010)²⁷⁴ which emphasises the local authority duty to provide support which sustain families so as to avoid '*children being required to take on inappropriate caring roles*' (para 24) and further advises:

25. Councils should identify any children or young people acting in a caring role and consider the impact on them. Community care packages should not rely on the input of an inappropriate level of care from a child or young person. In this respect, in addition to the provision of adult care assessment and support, councils should be prepared to address their duty under the Children Act 1989 to safeguard and promote the welfare of children in their area. The Children Act 1989 also specifies the need to take the views and interests of children into account. In discharging these duties, it is essential that Councils take account of the cumulative effects of responsibilities of family members within the household and where necessary, adult and children's services should work together to protect children from having to undertake unreasonable levels of care.

26. In the course of assessing an individual's needs, councils should recognise that adults who have parenting responsibilities

²⁷³ The English guidance (2000) is accessible at www.doh.gov.uk/scg/cin.htm and the Welsh (2001) at www.wales.gov.uk/subchildren/content/framework-m/framework-m.pdf - (see para 6.3 above).

²⁷⁴ Department of Health (2010) at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154. This advice has been augmented by a joint ADASS / ADCS publication *Working Together to Support Young Carers - A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services* (2009) at ADASS (2009) *Working Together to Support Young Carers - A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services* ADASS and ADCS, at www.adcs.org.uk/download/misc/working-together-to-support-young-carers-adcs-adass.pdf

for a child under 18 years may require help with these responsibilities.

28. As with adult carers, young carers should be given a range of information (appropriate to their age and understanding) and councils may wish to consider referring young carers and their families to any support services for young carers within their area.

Rights under the Carers (Recognition and Services) Act 1995

10.6 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 round²⁷⁵) but also whether they wish to undertake, education, training or any leisure activity.

Young carers and the Children Act 1989

10.7 There is no legislation which specifically refers to young carers. Guidance concerning young carers has, however, been issued by the Department of Health²⁷⁶ and Social Services Inspectorate (SSI).²⁷⁷ The SSI guidance adopts a definition of a ‘young carer’ as ‘a child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult’. 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 Health²⁷⁸ / Welsh Assembly²⁷⁹.

10.8 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

²⁷⁵ Para 10 Combined Policy Guidance under the 2000 and 2004 Acts.

²⁷⁶ Department of Health, Social Services Inspectorate (1998a) *Young Carers: Making a Start*. Department of Health, London.

²⁷⁷ Guidance letter 28.4.95; CI (95)12

²⁷⁸ Principally the *Framework for the Assessment of Children in Need and their Families* 2000, Stationery Office; accessible at www.dh.gov.uk/assetRoot/04/01/44/30/04014430.pdf and two volumes of guidance have been issued under the Children Act 1989 of relevance to young carers – Volume 2: *Family Support* and Volume 6: *Children with Disabilities* (both HMSO 1991).

²⁷⁹ *Framework for the Assessment of Children in Need and their Families* 2001 Stationery Office; accessible at www.wales.gov.uk/subchildren/content/framework-m/framework-m.pdf.

- 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.
- 10.9 The policy guidance under the 1995 Act (at para 14) referred to, and adopted specific guidance SSI ²⁸⁰ 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.²⁸¹
- 10.10 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 11.14 below).
- 10.11 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.
- 10.12 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.
- 10.13 Whilst the aim of a carers 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.

²⁸⁰ Guidance letter CI (95)12 Annex A para 1.1.

²⁸¹ 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'.

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’²⁸²

10.14 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.

10.15 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 Families*²⁸³ 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*

²⁸² Carers and Disabled Children Act 2000 policy guidance para 20 in England; para 2.5.1 of the Welsh guidance.

²⁸³ The English guidance (2000) is accessible at www.doh.gov.uk/scg/cin.htm and the Welsh (2001) at www.wales.gov.uk/subchildren/content/framework-m/framework-m.pdf: the cited extract appears at para 3.65 of the Welsh guidance.

(*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 Carers*²⁸⁴, 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.

- 10.16 As a result of amendments made by the Children Act 2004²⁸⁵, 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.

Law reform and young carers

- 10.17 As noted above (see para 3.39) proposals exist to codify social care law in England and Wales. In England a draft Care and Support Bill²⁸⁶ has been published and although aspects of it could lead to a strengthening of the rights of rights of adult carers, concerns have been expressed that the draft Bill as currently drafted could have unintended negative consequences for young carers.²⁸⁷
- 10.18 The draft Bill could obscure the right of young carers looking after an adult to have a carer's assessment as part of the community care assessment. The principle that adult social services departments should have responsibility for young carers was one that Malcolm Wicks MP fought to have enshrined in his 1995 Act – and the draft Bill if enacted in its current form, would be (in this respect) a retrograde step. Research suggests that around 70% of young carers look after an adult, so the identification of them by Adult Services is crucial.

²⁸⁴ Department of Health (1999) *Caring about Carers: A National Strategy for Carers*. Department of Health, London.

²⁸⁵ S17(4A) Children Act 1989 [inserted by s53 Children Act 2004].

²⁸⁶ Secretary of State for Health (2012) 'Draft Care and Support Bill' London: TSO Cm 8386 at www.dh.gov.uk/health/2012/07/careandsupportbill/

²⁸⁷ See for example, Bangs J and Clements L (2012) Carers and the Draft Care & Support Bill at www.lukeclements.co.uk/whats-new/

11. Parent carers

- 11.1 The importance of adequate and timely 'short break' / respite care for parent carers and has been specifically acknowledged by the English Government and is considered further at para 5.15 above.
- 11.2 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 1995²⁸⁸ 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'.²⁸⁹
- 11.3 Parent carers have a right to a separate assessment under the 1995 and 2000 Carers Acts 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 (in the Children Act assessment) 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.
- 11.4 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

²⁸⁸ 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 para 3 NHS Act 2006 and Sch 15 NHS (Wales) Act 2006 (which are community care services under s46 of the 1990 Act).

²⁸⁹ s72(6) Social Security Contributions and Benefits Act 1992

education activities) then parent carers may have to insist on having a separate assessment under the 1995 and 2000 Acts. It will be maladministration for a local authority not to undertake such a separate assessment or to suggest this is merely a ‘good will gesture’ – when it is in fact a statutory responsibility²⁹⁰. The right to such a separate assessment was put beyond doubt in *R (LH and MH) v Lambeth LBC* (2006)²⁹¹. 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).

- 11.5 The Ombudsman came to a similar finding in a 2009 complaint. It concerned a family that had a son whose autism was particularly challenging. This put enormous strain on both the parents and his younger sister. The local authority focussed exclusively on the needs of the son, without properly addressing the devastating impact his behaviour was having on his parents and sister. The ombudsman held that it was maladministration not to have undertaken separate carers’ assessments in this case.²⁹²
- 11.6 Notwithstanding the Courts and Ombudsman’s findings that parent cares have a right to a separate assessment, some local authorities continue to resist complying with this legal duty when so requested. In *HN (A Minor)* (2010)²⁹³ the High Court held that there was an ‘unconditional statutory obligation’ to carry out a carers assessment of a parent carer when requested so to do – within a reasonable period of time. In so finding the court observed:

What the Trust has done in this case has been to relegate the carer’s position as something inferior or secondary to that of the autistic child. For the reasons discussed above this was an incorrect approach to carer assessments. In taking this approach the Trust failed to recognise that the needs of the carer, the child and indeed the family are interlinked. This is

²⁹⁰ Public Service Ombudsman (Wales) Complaint No. B2004/0707/S/370 against Swansea City Council 22 February 2007 at para 131.

²⁹¹ [2006] EWHC 1190 (Admin) 25 May 2006

²⁹² Complaint No 07B 04696 and 07B 10996 against LB Croydon 16th September 2009, and see also Local Government Ombudsman’s *Digest of Cases (Education) 2008/09* Report 06B04654, pp14–15.

²⁹³ At www.bailii.org/nie/cases/NIHC/QB/2010/86.html a case concerning Article 18A Children (Northern Ireland) Order 1995 which in material terms, is indistinguishable from s1(2) Carers (Recognition and Services) Act 1995).

clear from an examination of the language, structure and clear statutory purpose of the legislative provisions.

- 11.7 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 carers assessment reliance can be placed upon the Government view that all 'carers who wish to work to have the right to work' (see para 4.63 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 child-care services. Many parents of disabled children would like to return to work and, if they were able to do so, would benefit socially and emotionally as well as financially.

- 11.8 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 final guidance.
- 11.9 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.
- 11.10 In this context, the above cited guidance to the 2000 Act (see para 4.61 above) is of particular importance – namely that if a carers' 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.
- 11.11 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.

11.12 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.

11.13 The Act was implemented in stages between 2006 and 2008 and is now (since April 2008) fully in force in both England and Wales.²⁹⁴

Disabled parents

11.14 A number of research reports²⁹⁵ 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

²⁹⁴ In this context, see the English Guidance: Department for Children, Schools & Families (2006) *Securing Sufficient Childcare: Guidance for Local Authorities Childcare Act 2006*; the Welsh Guidance WAGC 013/2008 - Guidance to Local Authorities – Childcare Act 2006 and see also at Office for Public Management (2008) *Reviewing Childcare Sufficiency Assessments* at www.everychildmatters.gov.uk/files/DCSF-OPM%20Report.pdf

²⁹⁵ See for instance the Social Services Inspectorate report *A Jigsaw of Services* (2000) accessible at www.dh.gov.uk/assetRoot/04/01/11/99/04011199.pdf, Olsen, R. & Tyers, H. *Supporting disabled adults as parents* (2004) National Family and Parenting Institute Ref N34 accessible at www.irf.org.uk/knowledge/findings/socialcare/n34.asp and the Commission for Social Care Inspection (2009) *Supporting disabled parents A family or a fragmented approach?* at www.cqc.org.uk/db/documents/Dis_parents6.pdf

research²⁹⁶ 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.

11.15 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’²⁹⁷ (para 9). This advice is amplified in further guidance in the following terms²⁹⁸:

... 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.

²⁹⁶ Olsen, R. & Tyers, H op cite.

²⁹⁷ Fair Access to Care Services (2002) Policy Guidance para 9 accessible at www.dh.gov.uk/assetRoot/04/01/96/41/04019641.pdf

²⁹⁸ 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/subisocialpolicysocialservices/content/managingcare.pdf

12. Carers and specific categories of service users

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' (the 'Care Programme Approach'): an assessment procedure that applies to all patients receiving care from the specialist psychiatric services – ie 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 services²⁹⁹ the Department of Health's 1999 National Service Framework for Mental Health³⁰⁰ 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).

²⁹⁹ Social Services Inspectorate. *Still Building Bridges* (The Stationery Office, London, 1999)

³⁰⁰ *A National Service Framework for Mental Health: Modern Standards & Service Models*. Department of Health (1999) 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.

12.4 The rationale behind Standard 6 is explained in the following terms:³⁰¹

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.³⁰² 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)³⁰³ 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

³⁰¹ A National Service Framework for Mental Health (as above) page 69

³⁰² A National Service Framework for Mental Health (as above) page 72.

³⁰³ Department of Health (March 2005) accessible at www.dh.gov.uk/assetRoot/04/10/53/69/04105369.pdf

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 type 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 roll 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

Carers of drug and alcohol misusers

12.8 People misuse drugs or alcohol, are entitled to community care services³⁰⁴ – no less than disabled, elderly and ill people. It follows that people who provide regular and substantial care for someone misusing drugs or alcohol are entitled to a carer's assessment – just like any other qualifying carer.

12.9 Historically carers of drug and alcohol misusers have been an overlooked group, because social services effectively delegate their community care service provision obligations for drug and alcohol misusers to the Drug Action teams / treatment Agencies.

12.10 Recent guidance has made some (but inadequate) steps to addressing this oversight. These include:

- The Home Office Action Plan for 2008 - 2011³⁰⁵. This however uses the term carer in a "quasi-parental" context although mention is made of young carers. Under 'Key action' (at page 13), it lists:

45. Support kin carers, such as grandparents, who take on caring responsibilities for the children of substance-misusing parents by exploring extensions to the circumstances in which local authorities can make payments to those caring for children classified as 'in need', backed up by improved information for carers, and guidance for local authorities, which may include a specific assessment for kin carers

and (at page 14)

49. Ensure that actions on young carers arising from the cross government carers review take account of the children of substance misusers

- The Home Office 2008 Drugs Strategy³⁰⁶ (which suffers from the same limitations as the Action Plan above) it nevertheless states at page 6 that its aim is to 'involve

³⁰⁴ Community care services are defined by s46(3) NHS & Community Care Act 1990 as being services that can be provided under various statutory provisions, including schedule 20 NHS Act 2006 and schedule 15 NHS (Wales) Act 2006, and Directions relating to these Acts make specific reference to drug and alcohol misusers – see Department of Health Circular LAC (93) 10 para 3(3)(g).

³⁰⁵ Home Office (2008) Drugs: protecting families and communities Action Plan 2008–2011 at <http://drugs.homeoffice.gov.uk/publication-search/drug-strategy/drug-action-plan-2008-2011?view=Binary>

³⁰⁶ Home Office (2008) Drugs: protecting families and communities The 2008 drug strategy

families and carers in the planning and process of treatment, for young people and for adults' and at page 21 a key aim of the strategy is stated as being:

Support kin carers, such as grandparents caring for the children of substance-misusing parents, by exploring extensions to the circumstances in which local authorities can make payments to carers of children classified as 'in need', backed up by improved information for carers and guidance for local authorities.

- National Treatment Agency for Substance Misuse Guidance *Supporting and involving carers* September 2006, which includes specific advice on the importance of addressing the needs of carers – and refers to the obligations on the NHS to include carers in service planning in accordance with tier duties under (what is now) National Health Service Act 2006, s242³⁰⁷.
- In Wales, Welsh Assembly Government guidance (2007) *Substance Misuse Treatment Framework Carers and Families of Substance Misusers A Framework for the Provision of Support and Involvement Consultation Document* – stresses the rights of carers to an assessment and that the duty to assess 'can be devolved to substance misuse providers by the local authority'³⁰⁸ and that there is an expectation that where contact is made with carers 'an assessment will be undertaken and a care plan produced and agreed with the carer by the Local Authority in accordance with the Unified and Fair Assessment system (para 8.3).

Carers and immigration controls

12.11 Carers may be subject to the UK's immigration controls – for example, they may be seeking asylum or seeking to remain so they can provide care for a sick or disabled relative or friend.

12.12 Immigration and Asylum law is notoriously complex and reference should in such cases be made to expert advice – as many such cases are highly 'matter specific'. However the fact that someone subject to immigration control is a carer is a relevant consideration in any determination as to whether s/he should be permitted to remain in the UK.³⁰⁹ The Home Office UK Border Agency has issued guidance as to how such

³⁰⁷ As amended by s233 Local Government and Public Involvement in Health Act 2007 (formerly s11 Health and Social Care Act 2001)

³⁰⁸ Whether, as a matter of law, such all responsibility for an assessment can be delegated, is questionable - see para 4.2 above – unless the substance misuse provider is itself part of the local authority

³⁰⁹ See for example *R v Secretary of State for the Home Department Ex parte Zakrocki* [1996] EWCA Civ 1326 at www.bailii.org/cgibin/markup.cgi?doc=/ew/cases/EWCA/Civ/1996/1326.html

applications should be considered³¹⁰ which includes the fact that applicants can qualify for entry clearance (under the 'carer concession') even if they are already in the UK (para 17.1.3).

- 12.13 Carers who are also seeking asylum or who are failed asylum seekers, are subject to specific provisions – for which general guidance has also been issued by the Home Office UK Border Agency.³¹¹

³¹⁰ Home Office UK Border Agency (2010) *Immigration directorate instructions* – chapter 7 of which contains advice concerning carers – accessible at www.bia.homeoffice.gov.uk/sitecontent/documents/policyandlaw/IDIs/idischapter17/section2/section2.pdf?view=Binary

³¹¹ Office UK Border Agency (2004) *Asylum seekers with care needs* Policy Bulletin 82 www.ukba.homeoffice.gov.uk/sitecontent/documents/policyandlaw/asylumsupportbulletins/general/ and see generally, Luke Clements and Pauline Thompson (2011) *Community Care and the Law* 5th edition (Legal Action) Chapter 21.

13. Carers equality and human rights

- 13.01 Whilst it is self evident that carers have the same human rights as any other person, it is only recently that the law has moved to recognise their non-discrimination rights – in the sense that they have a right not to be treated adversely because of their caring role. The Equality and Human Rights Commission's has also recognised how central considerations of equality and human rights are to the situation of carers. In its 2010 Equality Review³¹² it highlighted (as one of its five key note challenges) the importance of reducing 'the rise of the need for and cost of informal care, and to increase autonomy, choice and control for both carers and those who receive care.' Noting that unpaid carers contribution to the economy has been estimated at £87bn each year, the Report stressed the need for a reform of the state's economic and social approaches to caring.
- 13.02 This section commences with a brief review of human rights law as it specifically impacts on carers and then considers the extent to which the Equality Act 2010 directly and indirectly protects carers from discriminatory treatment.

Carers and human rights

- 13.03 Increasing attention is being paid to the idea that there is a substantive human right to 'care': it generally being accepted that there are additionally (in human rights terms): (1) 'positive obligations' on states to compensate carers for the adverse treatment they experience in consequence of their caring; and (2) obligations on states to ensure that they do not experience associative (or 'derivative' discrimination).³¹³
- 13.04 Article 8 of the European Convention on Human Rights (ECHR) places an obligation on public bodies to 'respect' the private and family lives of individuals. The duty (which is part of our domestic law – as a result of the Human Rights Act

³¹² Equality and Human Rights Commission (2010) *How fair is Britain?* Executive Summary p46 at www.equalityhumanrights.com/key-projects/triennial-review/

³¹³ See generally Clements, L (2012) 'Does your carer take sugar? Carers and human rights: the parallel struggles of disabled people and carers for equal treatment' at www.lukeclements.co.uk/whats-new/

1998) has been held to include a number of elements, for example a duty to refrain from unnecessarily interference in private / family life as well as a duty to take reasonable measures to ensure that individual and family life is sustained 'with dignity'.

- 13.05 The obligation of 'non-interference' was explained by Lord Justice Munby in a 2010 judgment³¹⁴ where he expressed concern about inappropriate interventions in the lives of families caring for disabled members: where the local authority seemed to believe that it was not merely 'involved' but that that it had 'complete and effective control ... through [its] assessments and care plans'. Of this he said (at para 52):

... the assertion or assumption, however formulated, betrays a fundamental misunderstanding of the nature of the relationship between a local authority and those, like A and C and their carers, who it is tasked to support – a fundamental misunderstanding of the relationship between the State and the citizen. People in the situation of A and C, together with their carers, look to the State – to a local authority – for the support, the assistance and the provision of the services to which the law, giving effect to the underlying principles of the Welfare State, entitles them. They do not seek to be "controlled" by the State or by the local authority. And it is not for the State in the guise of a local authority to seek to exercise such control. The State, the local authority, is the servant of those in need of its support and assistance, not their master. ...

- 13.06 The Ombudsman has also expressed concern about heavy handed action by councils. A 2008 complaint³¹⁵ concerned a local authority that was in dispute with a disabled child's family over the use of a hoist. Although it was accepted that the family were devoted to their son, the authority made an adult protection referral – asserting that their failure to use the hoist was putting him at risk. The Ombudsman (at para 37) held that it 'beggars belief that the referral was made at all'. A similar finding was made in relation to a 2009 complaint³¹⁶ which concerned a mother who (because of a service failure by the council) had no option but to hose her sons down in the back garden to keep them clean. Instead of providing adequate bathing facilities, she was warned by the council that this was 'abusive' – something that the Ombudsman considered to be of 'breathhtaking insensitivity' by a council that (in her opinion) exhibited an 'institutionalised indifference' not only to the disabled children's needs and the mother's plight but also to the Council's duties and responsibilities.

³¹⁴ *A Local Authority v A (A Child)* [2010] EWHC 978 (Fam).

³¹⁵ Complaint no 07/B/07665 against Luton Borough Council, 10 September 2008

³¹⁶ Complaint no 07/C/03887 against Bury MBC, 14 October 2009.

- 13.07 *R (Hughes) v Liverpool City Council* (2005)³¹⁷ is an example of the obligation on public bodies to take action to protect individuals and their families from harm and indignity. In this case, as noted at para 4.90 above, but for the extraordinary efforts made by a disabled person's carer (a burden the judge considered to be 'intolerable') the court would have found an article 8 violation of the young man's rights. The relevance of the positive obligations on local authorities and health bodies, under the European Convention on Human Rights, to carers has been flagged up by the English policy guidance, '*Prioritising need in the context of Putting People First*' (2010)³¹⁸ (para 100) which makes (amongst other things) specific mention of the *Liverpool* case in this context
- 13.08 In *R (A & B, X & Y) v. East Sussex County Council* (2003)³¹⁹ the court stressed that disabled peoples' rights under the ECHR had to be balanced against the corresponding rights of their carers (paid or unpaid). Accordingly in *R (Bernard) v Enfield LBC*³²⁰ the court found a violation of article 8 through the delay in the provision of accessible toileting for a disabled woman (as it 'would have restored her dignity as a human being) and it additionally found a violation of the article 8 (respect for family life) rights of her husband and children – as the failure of the council to take urgent action:
- condemned the claimants to living conditions which made it virtually impossible for them to have any meaningful private or family life for the purposes of Article 8
- 13.09 The article 8 rights of carers can also be engaged in cases where their immigration status is in dispute. In *Miao v Home Department* (2006)³²¹ for instance 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. This question is further considered at para 12.11 above.

Carers and the Equality Act 2010³²²

- 13.10 Since 1968 laws have been enacted in the UK challenging the discrimination that handicaps people in all walks of life. Initially it was race discrimination that was made unlawful, then discrimination based on sex and in 1995, discrimination against disabled people. In 2000 the *EU Equal Treatment Framework*

³¹⁷ [2005] EWHC 428 (Admin) 8 CCLR 243 paras 35 - 39.

³¹⁸ Department of Health (2010) at

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154

³¹⁹ [2003] EWHC 167 (2003) 6 C.C.L. R. 194 at para 116.

³²⁰ [2002] EWHC 2282 (Admin); (2002) 5 CCLR 577 at [33]

³²¹ [2006] EWCA Civ 75.

³²² Further analysis of the 'carer' related impact of the Equality Act 2010 is provided in *The Equality Bill and Carers* at www.carersuk.org/Professionals/ResourcesandBriefings/Policybriefings.

Directive required that in addition, there be protection (in the realm of employment law) in relation to discrimination based on age, religion and sexual orientation.

- 13.11 As a result of the landmark *Coleman v Attridge Law* (2008)³²³ ruling by the European Court of Justice in 2008, it was held that the Directive also protected the carers of disabled people 'by association': ie if they were discriminated because they were associated with a disabled person.
- 13.12 In addition, in Wales s35 and s77 Government of Wales Act 2006 places an obligation on the Assembly and the Welsh Ministers to discharge their functions 'with due regard to the principle that there should be equality of opportunity for all people'.
- 13.13 The result of over 40 years of incremental development of non-discrimination legislation meant that the UK had accumulated a wide ranging and complex body of law – which was in need of codification. This has now been done with the enactment of the Equality Act 2010 – the major provisions of which came into force on the 1st October 2010. In due course (when the remaining provisions of this Act are in force) the previous legislation (except the Government of Wales Act 2006) will be repealed and all claims for unlawful discrimination will be based on this Act.
- 13.14 The Act prohibits less favourable treatment based of nine 'protected characteristics' which are detailed in ss4-12, namely: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex and sexual orientation. Carers are not (yet) included in this list, but because of the *Coleman* judgment and for associated reasons they will often gain protection.
- 13.15 Despite the best efforts of those drafting the 2010 Act, the law in this field remains complex and the analysis that follows can be no more than a brief outline.
- 13.16 The Act contains three specific and important provisions which will enable carers to challenge adverse treatment they experience as a result of their caring responsibilities. These are considered separately below under the sub-headings (1) associative discrimination; (2) indirect discrimination; and (3) impact assessments. It should however be appreciated that these categories are not always distinct – such that action that amounts to unlawful associative discrimination may also be expressed as unlawful indirect discrimination (and vice versa).

³²³ *Coleman v Attridge* ECJ C-303/06 Judgment 17 July 2008 accessible at <http://curia.europa.eu/jurisp/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-303/06>

1. Associative discrimination

13.17 Section 13 of the Act makes it unlawful to treat a person less favourably because of a protected characteristic. The person, however need not have the relevant characteristic. For example a mother might feel she is being treated unfairly by her employer, who denies her time off work to care for her disabled child, even though the employer allows other staff time off work for other activities. This is exactly what Sharon Coleman claimed had happened to her. Although she is not a disabled person, her unfavourable treatment was disability related.

13.18 Associative discrimination arises therefore where a policy or practice aimed at someone associated with a protected characteristic (i.e. disability or sex or race etc) disadvantages the person with the protected characteristic. In relation to carers, it is probably best understood where a disadvantage can be expressed in the following simple statement: *'but for my relationship with the disabled or older person, this would not have happened.'* Examples of responses could be:

- *'I would not have been forced to leave my job'* – as was the case argued by Sharon Coleman.
- *'I would have got the bank loan'* – as was the case of a carer who was denied a bank loan because his disabled son lived with him.

13.19 The Statutory Code of Practice issued by the Equality and Human Rights Commission³²⁴ concerning 'Services, Public Functions and Associations' provides two useful (though similar) examples, namely:

The guest at a club dinner is the full-time carer of a disabled child with learning difficulties. The club excludes her and the child from the association's main dining room. The carer could complain of direct discrimination because of disability – in this case the disability of the child with whom she is associated. (page 176)

2. Indirect discrimination

13.20 Section 19 of the Act makes unlawful certain types of 'indirect discrimination'. Indirect discrimination arises when an apparently neutral provision or practice puts a person with a protected characteristic (e.g. sex, race, disability) at a particular disadvantage compared with other people (unless the provision can be objectively justified). A classic example of such action was a minimum height requirement that used to be applied by

³²⁴ Equality and Human Rights Commission (2011) Equality Act 2010 Code of Practice: Services, public functions and Associations Statutory Code of Practice at www.equalityhumanrights.com/uploaded_files/EqualityAct/servicescode.pdf

the police to new recruits. Although this was neutral (in the sense it applied everyone) it put women and some racial groups at a disadvantage, since they tend to be shorter. Where it is established that a provision or practice is having a disparate impact on a particular group, then the Act requires that the responsible person or organisation justify its use.

13.21 In order to establish that unlawful indirect discrimination has taken place, it is often necessary to provide evidence that a policy is having an adverse disparate impact. Such evidence can be obtained from a variety of official statistics that may be readily available – such as the annual performance indicator returns made by authorities. For example, local authority National Indicator 135³²⁵ – requires that councils record the number of carers helped following a carers assessment expressed as a percentage of all service users. Analysis of this figure may highlight disparities in various impairment sectors – eg that significantly fewer carers of people with mental health difficulties get help compared to those caring for people with other impairments.

13.22 The extent to which carers will be able to benefit from the Act's indirect discrimination provisions, is unclear. However, given that more women are carers than men, in certain situations the carer may be able to rely on straightforward indirect sex discrimination, as the example in the Statutory Code on 'Services, Public Functions and Associations' (para 5.11) illustrates:

When a local council holds its consultation meetings on a weekday evening, it discovers that fewer women than men attend. A woman complains that this is because the women (including herself) cannot come because of childcare responsibilities. This is enough to demonstrate disadvantage and she does not have to show that the absence of women is attributable in particular cases to childcare responsibilities.

13.23 In such cases, where the difference is well known there is no need for the complainant to establish it as a matter of fact – as the example in the Statutory Code of Practice issued by the EHRC on 'Employment' at para 4.22 explains:

It is accepted as common knowledge that men are far less likely than women to be single parents with childcare responsibilities.

³²⁵ Audit Commission NI 135 'Carers receiving needs assessment or review and a specific carer's service, or advice and information' - see www.audit-commission.gov.uk/localgov/audit/nis/Pages/NI135Carersreceivingneedsassessmentorreviewandaspecificcarer%E2%80%99service,oradviceandinformation.aspx
<http://www.communities.gov.uk/documents/localgovernment/pdf/505713.pdf>

- 13.24 The potential impact of the ‘indirect discrimination’ provisions can be explored by considering the familiar problem many carers experience, of agencies that have inflexible appointments arrangements, for example, GPs. Frequently a carer will have to make advance arrangements (for a substitute carer) before being able to visit their GP. If the surgery only allows appointment times to be booked on the morning of the day required, then this policy will have an indirect adverse impact on carers – since although it is an apparently neutral provision (as it applies to everyone) it puts the carer at a particular disadvantage compared with other people (who do not have caring responsibilities).
- 13.25 However the Act only prohibits indirect discrimination in relation to a protected characteristic (i.e. age or disability). The carer would therefore have to show that the inflexible appointments policy ‘puts or would put’ (to quote the wording of the Act) the disabled or older person at a disadvantage. Not infrequently this will be the case – for example, when a carer becomes unable to care because of an illness caused or exacerbated by not being able to visit the GP.

3. Public sector equality duties

- 13.26 The Equality Act 2010 s149 imposes duties on public authorities (such as local authorities, the NHS, and Government Departments) to take action aimed at eliminating discrimination, advancing equality of opportunity and fostering good relations. This is often referred to as the ‘public sector equality duty’ and it has been the subject of extensive litigation.³²⁶
- 13.27 In *R (Brown) v Secretary of State for Work & Pensions* (2008)³²⁷ the Administrative Court identified 6 key principles associated with the public sector equality duty. Although these relate to a disability discrimination claim, they read across into discrimination engaging other ‘protected characteristics’. The principles being that the duty is (1) a general obligation; (2) it has to be considered before the relevant decision is made; (3) it is ‘a substantial one’ - to have ‘due’ regard; (4) it is non-delegable; (5) it is a continuing duty; and (6) it is a duty of record (if the public body does not have a contemporaneous written record that it had had ‘due regard’ then the courts will consider that it was not discharged).
- 13.28 One important aspect of the duty is the requirement that public bodies must consider the impact of their policies and practices

³²⁶ See for example, *R (W) v. Birmingham CC* [2011] EWHC 1147 (Admin) and for an overview of the public sector duty, see for example Broach, S. Clements, L. and Read, J. (2010) *Disabled Children: a legal handbook* (Legal Action Group) para 9.73 – 9.90.

³²⁷ [2008] EWHC 3158 (Admin) (paras 84 – 96).

– and to take compensatory action if any of them are (for instance) shown to have the potential to be discriminatory or to insufficiently advance equality of opportunity. This duty applies not only to new policies, but also to existing practices: which should be reviewed to see ensure that they advance the authority's 'equality duties'.

- 13.29 Since the 2010 Act does not make discrimination against carers 'per se' unlawful the duty on every public body will be to review its new and existing policies and practices to ensure that they do not have the potential to discriminate indirectly or by association. For example, before an NHS hospital introduces an appointments system (e.g. one on similar lines to that of the GP practice considered above) it would need to undertake an assessment, to ensure it did not have an adverse impact on carers, since this could (as considered above) result in indirect discrimination on grounds of sex and potentially associative discrimination on grounds of disability and/or age.
- 13.30 Equality Impact Assessments are likely to provide an important mechanism for increasing awareness of carers' needs and carers' rights through large parts of the public sector. They have the great advantage of being 'proactive' – ie not only applying when something has gone wrong. Many organisations are already adapting their policies to ensure that they advance equality of opportunity for carers. For example the Care Quality Commission's Equality and Human Rights scheme³²⁸ places very considerable emphasis on the need to support carers – specifically acknowledging 'the importance of carers within the wider personalisation agenda, and ... that carers can play a central role on better integration between health and adult social care and that carers themselves have their own needs and human rights'.
- 13.31 The obligation on public bodies to undertake an impact assessment may prove to be valuable tools for carers' organisations to challenge where carers feel that their needs have been overlooked. A recent and well publicised example, might illustrate the value of such an 'impact assessment'. In 2008 the (then) Government's revised Carers' Strategy³²⁹ committed significant extra funding in England to NHS Primary Care Trusts (PCTs) to enable them to provide 'breaks' for carers from their caring responsibilities. Many PCTs chose not to use this money, for this purpose, but to use it instead for general (non-carer related) NHS purposes.³³⁰ The decision to do this was clearly a policy decision that had an adverse impact on disabled people – since respite care is at law a

³²⁸ See www.cqc.org.uk/db/documents/FINAL_PDF_Equality_and_Human_Rights_Scheme.pdf

³²⁹ Department of Health (2008) Carers at the heart of 21st-century families and communities. Para 3.11.

³³⁰ See for example Princess Royal Trust (2009) *Trust calls for Primary Care Trusts to fund respite breaks* Press Release August 6, 2009.

service for them, not carers.³³¹ It was also a decision that could 'put or would put' disabled people at a disadvantage. Arguably no PCT could have taken this decision without undertaking (what is now) an Equality Act 2010 s149 impact assessment.

³³¹ See *Carers and their Rights* (footnote 5 above) para 5.7.

14. Complaining

Carers Complaints

14.1 Where carers are dissatisfied with the treatment they have received from a local authority or the NHS they are entitled to complain: for instance, if a carer has been treated rudely, or is 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 7.25 above). A carer will also be entitled to complain in their own right if refused an assessment or a service – for example if a council decided that she was not a qualifying carer, (see, in this context, para 3.30 above).

Representative complaints by carers

14.2 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.

14.3 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.

14.4 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 (see para 14.9 below concerning confidentiality issues). Whilst good practice might require that these formalities are evidenced in writing, this may not always be feasible: for instance if the person has suffered a relapse or is otherwise unable to do so.

2. Where the disabled person lacks mental capacity.

14.5 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.³³²

14.6 In all but the most exceptional cases a carer will self evidently be someone with a sufficient interest to bring such a complaint³³³. If the authority is for any reason uncertain as to whether to proceed, its analysis would require it to consider the matter from the perspective of what is in the disabled person's 'best interests'³³⁴ (see para 14.9 below). 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,³³⁵ authorities should be very cautious about deciding that a carer is not suitable.

³³² These two criteria are specifically identified as the key criteria by the National Health Service (Complaints) Regulations 2004 SI No. 1768, reg 8.

³³³ 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

³³⁴ ie under s4 Mental Capacity Act 2005

³³⁵ Because the authority could be accused of making such a finding to fend off an otherwise valid complaint

- 14.7 Where, unusually, an authority concludes that a carer is not suitable as a representative; it will 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. In such cases the authority will then have to decide whether nevertheless the complaint raises concerns that ought to be investigated.

3. Where the carer is not considered a 'representative'

- 14.8 Where a carer is deemed not to be acting as the disabled person's representative, the authority will have to consider whether the substance of the allegations is such that (a) the carer has a right to complain in his/her own right (see para 14.1 above) 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'.³³⁶ The NHS Ombudsman has taken a similar line – see para 14.11 below.

Confidentiality

- 14.9 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 2007 Code to the Mental Capacity Act 2005 provide some assistance in relation to the extent of disclosure in such cases:

16.19 Healthcare and social care staff may disclose information about somebody who lacks capacity only when it is in the best interests of the person concerned to do so, or when there is some other, lawful reason for them to do so.

16.20 The Act's requirement to consult relevant people when working out the best interests of a person who lacks capacity will encourage people to share the information that makes a consultation meaningful. But people who release information

³³⁶ Complaint No. 94/C/2959 against Nottingham City Council; 28 November 1994 and see also Complaint No 97/C/1614 against Bury MBC (1999).

should be sure that they are acting lawfully and that they can justify releasing the information. They need to balance the person's right to privacy with what is in their best interests or the wider public interest

16.21 Sometimes it will be fairly obvious that staff should disclose information. For example, a doctor would need to tell a new care worker about what drugs a person needs or what allergies the person has. This is clearly in the person's best interests.

16.22 Other information may need to be disclosed as part of the process of working out someone's best interests. A social worker might decide to reveal information about someone's past when discussing their best interests with a close family member. But staff should always bear in mind that the Act requires them to consider the wishes and feelings of the person who lacks capacity.

16.23 In both these cases, staff should only disclose as much information as is relevant to the decision to be made.

- 14.10 A failure by a health or social services authority to undertake a 'best interests' assessment as to the disclosure on information in such cases, could amount to maladministration. The Local Ombudsman in a complaint's report³³⁷ has, for instance, criticised a local authority for not sharing information with the parents of an adult with learning disabilities, stating:

I accept that this would not be regular practice when the Council is looking after an adult: the privacy of the individual demands that the parents be kept at some distance. But [the user] had such a high level of dependency that the Council should have been willing to reconsider its approach to parental involvement in this case.

- 14.11 In similar terms the NHS Ombudsman has upheld a complaint,³³⁸ which concerned an NHS Trust's refusal to respond to a complaint made by a friend of a patient with dementia. The Trust had cited 'patient confidentiality'; 'the Data Protection Act' and had agreed to 'take up the matters' with the patient's sister. The Ombudsman's held that 'while patient confidentiality is a legitimate consideration when deciding whether a representative is a suitable complainant, the Trust did not adequately explain to Mr P why it should not respond to his complaints. Nor did it demonstrate that it had adequately considered the NHS Complaints Regulations or the relevant legislation in reaching its decision'. The Ombudsman found no evidence that the Trust had established whether the disabled

³³⁷ Complaint no 97/C/4618 against Cheshire, 1999.

³³⁸ Parliamentary and Health Service Ombudsman (2008) Annual Report 2007-08 Complaint against Bedfordshire and Luton Mental Health and Social Care Partnership NHS Trust Case Study 15 page 37.

person was capable of providing consent for the release of confidential information to his friend, or considered if he had given implied consent for its release. In the Ombudsman's opinion there was no evidence that the Trust had considered whether there was any overriding public interest reason that required disclosure for disclosing information to the friend, or if any aspects of his complaint could be responded to without releasing confidential information.

- 14.12 Research suggests that some professionals use 'confidentiality smokescreens' as a way of withholding information from carers.³³⁹ Research also provides evidence of good practice in such cases, for instance that social and health care professionals should anticipate such problems and negotiate advance agreements when the disabled person has the capacity to consent and insight into their needs³⁴⁰ or ensure that disclosure of non-sensitive material is made – with the sensitive data excluded or typex'ed out etc.
- 14.13 The above good practice advice is reinforced by General Medical Council³⁴¹ guidance which also advises (for example) that 'unless they indicate otherwise, it is reasonable to assume that patients would want those closest to them to be kept informed of their general condition and prognosis' (para 65).
- 14.14 A detailed consideration of local authority and NHS complaints procedures lies outside the scope of this Guide³⁴² and the procedures in England were reformed in April 2009. Prior to the reforms the procedures required that social services authorities investigated complaints (if needs required) in three distinct stages, namely:
- 1) the informal or problem-solving stage;
 - 2) the formal or registration stage;
 - 3) the review stage.

In Wales the three stage process remains – and is described in 'Your rights to complain'.³⁴³

- 14.15 In England, April 2009, there is a single approach for dealing with complaints about NHS and adult social care services. Instead of the three stage system a less rigid process will be

³³⁹ Gray, B. Robinson, C. Seddon, D. and Roberts, A (2008) 'Confidentiality smokescreens' and carers for people with mental health problems: the perspectives of professionals in Health and Social Care in the Community (2008) 16 (4), 378–387

³⁴⁰ See for example, Rapaport J., Bellringer S., Pinfold V. & Huxley P. (2006) Carers and confidentiality in mental health care. *Health and Social Care in the Community* 14, 357–365.

³⁴¹ Confidentiality Guidance issued by the General Medical Council (12 October 2009) at www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp para 57 - 66.

³⁴² For a detailed explanation of the procedures, see Clements, L and Thompson P, (2011) *Community Care and the Law*, Legal Action Group, London chapter 26.

³⁴³ Accessible at <http://new.wales.gov.uk/>.

developed by individual authorities enabling them to adopt different approaches, determined by the nature and seriousness of the complaint. If a complainant remains dissatisfied, then s/he has the right to go to the Ombudsman. Local authorities are required to: (1) continue to have a nominated (senior) person responsible for the procedures; (2) to enhance the opportunities for complainants to have advocacy support; and (3) to provide complainants with a simple explanation as to how the complaints process works and the relevant timescales.

Ombudsman

14.16 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 them.³⁴⁴

³⁴⁴ 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/

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

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- campaigns for the changes that make a real difference for carers.

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Dr Hywel Francis MP who promoted the Carers (Equal Opportunities) Act 2004, Lord Tom Pendry who promoted the Carers and Disabled Children Act 2000 while an MP and Malcolm Wicks who promoted the Carers (Recognition and Services) Act 1995.

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