

Carers and their rights

England

Professor Luke Clements



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Forewords

**Foreword from Baroness Pitkeathley OBE,
Vice-President of Carers UK and Member of the House of Lords**

I am delighted to see this vital publication being updated to reflect the historic new rights for carers as part of the Care Act 2014, the Children and Families Act 2014 and other relevant guidance and legislation.

Having sought amendments and campaigned for better rights for carers in legislation, I know that rights in law, while vital, are only ever the first step. Making sure that they are implemented, and with the best knowledge possible of what is correct, makes all the difference. I hope that professionals and carers alike will use this guide to ensure that carers' rights are secured and promoted to the benefit of all.



**Foreword from Heléna Herklots,
Chief Executive of Carers UK**

Since we were first established in 1965, Carers UK has worked to make life better for carers, fighting for their rights to be recognised and to receive the right support for the person that they care for as well as for themselves.

This sixth edition of Carers and their Rights reflects the development of those entitlements over the last half century, giving us expert interpretation of the key pieces of legislation where carers' rights matter. We are delighted to have had the support, wisdom and skill of Professor Luke Clements working with us over the years to improve carers' rights and to ensure the clarity of interpretation of complex areas of law.

With the new Care Act 2014 and the Children and Families Act 2014 now in place and operational, the hard work begins to turn those rights into a reality for carers. In a tight fiscal environment, knowing what duties public authorities have towards carers of all ages becomes increasingly important. We hope that this vital guide will help public authorities build better services and support for carers and their families, as well as help advocates seek the best for the people they represent.



1. Introduction

- 1.1 The Care Act came into force in 2015: the 50th anniversary of the founding of the Carers Movement in the UK.
- 1.2 This edition outlines the principal rights of carers to support from health and social services authorities in England. As before, this guide does not seek to address carers' entitlement to welfare benefits – but at 8.1 links are given to information sources where this information can be obtained.
- 1.3 This edition does not cover the law as it applies in Wales. The reason for this departure is that the law concerning carers' rights is now so distinct that separate guides are necessary.
- 1.4 This edition has involved a fundamental rewriting of the Guide to take into account the enactment of the Care Act 2014¹ – which repeals most of adult social care law in England (including the majority of the Care Acts). The 2014 Act very substantially improves the legal rights of carers. This is done by various changes, most prominently:
 - By removing the requirement that a carer (in order to qualify for support) has to provide, or intend to provide, 'a substantial amount of care on a regular basis';²
 - By removing the requirement that carers have to 'request' an assessment; and
 - By placing a duty on local authorities to meet carers assessed needs (under the previous legislation there was only a 'power' in such cases).
- 1.5 The law relating to young carers and parent carers in England has also undergone major reform – as a result of the enactment of the Children and Families Act 2014.³ The Act entitles parent carers and young carers to an assessment of their needs regardless of how much care they provide and it places a duty on councils to identify young carers and parent carers within their areas.
- 1.6 The new legislation represents further evidence of the major cultural shift 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. This shift in approach was evident in the Carers (Equal Opportunities) Act 2004 and the Work and Families Act 2006 – but is taken much further by the 2014 Act – which (as the Government has sought to emphasise) provides carers with 'the first ever

¹ The relevant provisions of this Act came into force on the 1 April 2015.

² This requirement first appeared in the Disabled Persons (Services, Consultation and Representation) Act 1986, section 8 and was then adopted by the Carers (Recognition and Services) Act 1995 section 1 (and subsequent Carers Acts).

³ The relevant provisions of this Act, sections 96 and 97, came into force on the 1 April 2015.

legal entitlement to public support, putting them on the same footing as the people for whom they care.⁴

- 1.7 The depth of the social exclusion experienced by the UK's 6.5 million carers⁵ stands in sharp contrast to these new rights. With the tightening of social care budgets, this disparity is becoming ever more obvious. Between 2009 and 2013 spending on social care for older people fell by 15% in real terms and 250,000 fewer older people received publicly funded community services (a 26% fall). The problems of social care are not therefore caused by the rise in the number of older people but by Government spending cuts.⁶ The consequent hardships in terms of income poverty, poor health and isolation borne by carers are severe and cited throughout this guide (see for example para 5.32 below).
- 1.8 The social and economic marginalisation of carers is not new – and their present problems are not a ‘blip’ caused by the current financial difficulties. Ever since the implementation of the 1993 community care reforms there has been a steady increase in the numbers of carers⁷ - reflecting what is best described as the ‘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 There has been an 11% increase in the number of carers from 2001 to 2011.¹⁰ Today fewer people are receiving social care support from local authorities – with the inevitable consequence that their carers are taking the strain.¹¹
- 1.9 The Government’s message concerning the Care Act 2014 stresses the major advance it represents in terms of the legal rights for carers. None of these rights will materialise unless they are accompanied by a major advance of resources to make them a practical reality. In this context an observation made by Lord Lloyd is apt – it was made almost 20 years ago in relation to a similar notable Act: ‘The solution lies with the Government. The passing of the Act ... was a noble aspiration. Having willed the end, Parliament must be asked to provide the means’.¹²

⁴ Department of Health *The Care Bill explained: Including a response to consultation and pre-legislative scrutiny on the Draft Care and Support Bill* Cm 8627 (The Stationery Office 2013) para 73.

⁵ Census 2011.

⁶ S Ismail, R Thorlby & H Holder *Focus On: Social care for older people, Reductions in adult social services for older people in England* (The Health Foundation and Nuffield Trust 2014) and see also *LGA Adult social care funding: 2014 state of the nation report* (Oct 2014).

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.*

¹⁰ Department of Health (et al.), *Adult social care in England: overview* (2014)

¹¹ 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 and Department of Health (et al.), *Adult social care in England: overview* (2014).

¹² *R v Gloucestershire County Council ex p Barry* [1997] 2 WLR 459; (1997) 1 CCLR 40.

2. Definitions

The statutory scheme

- 2.1 The Care Act 2014 radically reforms adult social care law in England. The main provisions in the Act came into force in April 2015 and repealed virtually all the previous social care legislation including the three Carers Acts (with one small exception).¹³
- 2.2 The provisions of the Act are fleshed out in regulations and in addition by 500 pages of statutory guidance that explains the Act's underlying purpose and the obligations it imposes.¹⁴ The guidance is likely to be of considerable importance – in much the same way that the policy guidance accompanying the Community Care reforms in 1993¹⁵ proved to be highly influential in shaping that system. The guidance is referred to as statutory guidance as it is issued under section 78 of the 2014 Act which means that local authorities are 'required to act under' it – that they must follow it, unless they can demonstrate sound legal reasons for not doing so.

Who is a carer?

- 2.3 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.
- 2.4 The Care Act 2014, section 10(3) defines a carer as an 'adult¹⁶ who provides or intends to provide care for another adult'. The Act excludes carers who provide this care on a paid basis or as a formal volunteer (see para 2.7 below). The Care Act 2014 and the Children Act 1989 provide for the rights of 'young carers' (ie those under the age of 18) and for people providing care for disabled children – and these provisions are considered separately below (see chapter 10 for young carers and chapter 11 for parent carers).
- 2.5 The Care Act 2014, section 10(3) definition of a carer marks a significant change. Under the pre-Care Act legislation, in order to qualify for an assessment, a carer had also to provide (or intend to provide) 'a substantial amount of care on a regular basis'.¹⁷ All 'carers' are now eligible for an

¹³ The Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 are all repealed in England with the exception of section 1 of the 1995 Act – see para 11.12 below.

¹⁴ References in this publication to the guidance are correct as of end of April 2016.

¹⁵ Department of Health (1990) *Community Care in the Next Decade and Beyond: policy guidance*.

¹⁶ The Act has provisions for 'young carers' (ss63-64) – i.e. people who are under 18 – but these provisions use the term "young carers".

¹⁷ This requirement first appeared in the Disabled Persons (Services, Consultation and Representation) Act 1986, section 8 and was then adopted by the Carers (Recognition and Services) Act 1995 section 1 (and subsequent Carers Acts).

assessment. This means that many more carers will be eligible for an assessment – for example those who are providing little or no physical or practical care – but providing emotional support by visiting adult disabled or older people living elsewhere – either in their own homes, supported living, care homes or psychiatric wards, etc.

- 2.6 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

- 2.7 As with the pre-Care Act law,¹⁸ there is no duty to assess carers who provide their care by virtue of a contract, or as voluntary work (section 10(9)). The statutory guidance¹⁹ to the Care Act 2014 addresses the not uncommon situation of a carer who is paid to provide care for the adult (possibly through the use of a direct payment – see para 6.18 below) but is also providing unpaid care for that person. At para 6.17 of the guidance it advises that in such circumstances ‘the local authority must consider whether to carry out a carer’s assessment for that part of the care they are not providing on a contractual or voluntary basis’. This issue is considered further at para 6.23 below.

Adults needing care

- 2.8 The Care Act defines a carer by reference to his or her caring role in respect of an ‘adult needing care’.²⁰ The Act does not define what is meant by an ‘adult needing care’ but the relevant eligibility criteria²¹ require that these needs ‘arise from or are related to a physical or mental impairment or illness’. These terms are not defined either, although the statutory guidance advises (para 6.102) that this includes ‘physical, mental, sensory, learning or cognitive disabilities or illnesses, substance misuse or brain injury’. It is therefore almost certain that ‘adults needing care’ will be given a very wide interpretation (as with the equivalent terms under the previous legislation²²). Accordingly it will cover not only those whose illness is caused by the misuse of drugs or alcohol²³ (see para 12.12 below) but also those with ‘any disorder or disability of the mind’.²⁴ This latter category would comprise such conditions as depression, dementia, learning disability, personality disorder

¹⁸ Section 1(3)(a) Carers (Recognition & Services) Act 1995 and section 1(3)(a) Carers & Disabled Children Act 2000.

¹⁹ Department of Health Care and Support revised Statutory Guidance (DH 2016)

²⁰ For discussion concerning ‘young carers’ and parent carers, see chapters 10 and 11 respectively.

²¹ The Care and Support (Eligibility Criteria) Regulations 2014

²² Section 29 National Assistance Act 1948 defined disabled people as people who were ‘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’ and section 17(11) Children Act 1989 contains a similar definition – see para 9.3 below.

²³ See Schedule 20 NHS Act 2006 and the relevant Directions specific to drug and alcohol misusers, contained in Department of Health Circular LAC (93) 10 para 3(3)(g).

²⁴ I.e. within the ambit of section 1 Mental Health Act 1983.

as well as hyperactive/attention deficit disorders,²⁵ ‘high functioning’ autism and Asperger’s syndrome. In this context the statutory guidance advises (para 6.105) that authorities ‘should base their judgment on the assessment of the adult and a formal diagnosis of the condition should not be required’.

What is ‘care’?

- 2.9 The 2014 Act does not seek to define ‘care’, although the statutory guidance states that it ‘includes both the practical and emotional support’ (para 6.18). Since care is directed towards enhancing individual well-being, this brings with it a requirement to consider the section 1 checklist – including the ‘physical and mental health and emotional well-being’.
- 2.10 Pre-Care Act guidance has recognised that in law ‘caring’ is a much wider concept than simply providing physical or practical care – stating, for example, that care may relate to being ‘anxious and stressed waiting for, or actively seeking to prevent, the next crisis’.²⁶ It has also suggested that it encompasses both the notion of ‘caring about someone’ as well as ‘caring for them’.²⁷
- 2.11 It is perhaps unlikely that disputed cases will arise requiring resort to the Oxford English Dictionary.²⁸ Courts are likely to accept that care has a wide meaning – and that people’s perception of themselves as ‘caring’ should in general be accepted and an assessment offered to them (which might be a relatively brief process in some cases). The pre-Care Act requirement that carers establish that their care was ‘regular and substantial’ attracted little court or ombudsman attention²⁹ – most probably for the same reason: namely that it is difficult to determine the question until an assessment had been undertaken. In one of the few reported cases where a local authority did refuse to assess a carer (because it did not consider his care sufficiently ‘substantial’) the Local Ombudsman observed:³⁰

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 ...; and (b) what practical help could be provided to [the carer] with respite from his caring responsibilities.

²⁵ Sometimes referred to as Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD) – see also para 9.3 below.

²⁶ See for example, Department of Health *Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance* (2000) para 67-8; Welsh Assembly Government *Guidance 2000 Act* (2001) para 4.11 and Welsh Government (2012) *Carers Strategies (Wales) Measure 2010 Guidance* issued to Local Health Boards and Local Authorities, Annex 2.

²⁷ Department of Health *Carers (Recognition & Services) Act 1995 Practice Guidance* LAC (96)7 at para 9.8; WOC 16/96 and WHC (96)21 in Wales (also at para 9.8).

²⁸ The OED’s account of the etymology of the verb ‘to care’ shows a migration from its Old High German origin ‘chara’ (trouble, grief, care): from essentially ‘grieve’ to ‘feel concern’ and ‘look after/take care of’ – although the emotional element remained central until the mid-Victorian period. The shift is evident in an 1887 Manchester Guardian report which noted: ‘The child had ... been well cared for.’ It appears that the first printed use of the word ‘carer’ in its modern sense is as recent as 1978 when the OED references ‘Age & Ageing VII. 107 *A much lower proportion of patients with chief carers in social classes one and two were admitted than those in three, four and five*’ and even until 1980 the OED notes that word carer was still put between inverted commas.

²⁹ See for example, Luke Clements *Carers and their Rights* 5th ed (Carers UK 2012) para 3.30 and Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004, and see also complaint no. 05/C/11921 (Trafford MBC) on 26th July 2007.

³⁰ Complaint no. 02/C/08690 against Sheffield City Council 9th August 2004, and see also complaint no. 05/C/11921 (Trafford MBC) on 26th July 2007.

- 2.12 The Care Act 2014 uses the phrase ‘care and support’ to describe the potential needs of disabled, elderly and ill adults. When discussing how local authorities should respond to the needs of carers it uses the word ‘support’ only, on the basis that carers do not need ‘care’ but they may require ‘support’ for their caring role.

‘Intending to provide’

- 2.13 The definition of a carer in section 10(3) of the 2014 Act includes those who are not providing care – but who ‘intend to’. Neither the Act nor the statutory guidance provide further detail on this point. The provision first appeared in section 1 of the Carers (Recognition and Services) Act 1995 and was largely directed at hospital discharges (see para 7.14 below). The guidance that accompanied the 1995 Act explained:³¹

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.

Social Services

- 2.14 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.

³¹ Department of Health *Carers (Recognition & Services) Act 1995 Practice Guidance* LAC (96)7 para 16.

3. Social services obligations to carers – an overview

Introduction

- 3.1 Since 1986 when carers were first mentioned in social care legislation³² their official recognition has grown dramatically. In the first two decades 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.³³ 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 The activism of the ‘carers’ movement³⁴ has used the law to challenge the marginalisation and social exclusion that carers experience. Initially this was evidenced by the promotion of a series of Private Members Bills³⁵ and subsequently by the ‘mainstreaming’ of carer specific provisions in Government promoted legislation – for example the Work and Families Act 2006, the Childcare Act 2006, the Equality Act 2010 and most recently and most prominently, the Care Act 2014.
- 3.3 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’.³⁶ The strong probability exists that the comments of the Commission for Social Care Inspection remain as pertinent today as they did in 2006, that:³⁷

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.

³² Disabled Persons (Services, Consultation and Representation) Act 1986, section 4.

³³ Twigg J. & Atkin K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham describes 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.

³⁴ For a discussion concerning the development of the global ‘carers movement’ Luke Clements (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/

³⁵ Three of these Bills succeeded Parliamentary approval: The Carers (Recognition and Services) Act 1995; the Carers and Disabled Children Act 2000; and the Carers (Equal Opportunities) Act 2004.

³⁶ See for example the stark statistics cited at para 5.32 below.

³⁷ CSCI (2006) *The State of Social Care on England 2005-2006* (CSCI December 2006) page iv.

- 3.4 In 2009 this view was echoed by the House of Commons Health Committee – namely that the social care system was no longer ‘fit for purpose’: a system that ‘places unfair and unreasonable demands on carers’.³⁸ The unfairness of the system derives from the lack of resources devoted to the system and not the technical phrasing of the legislation.

Overview of current responsibilities

- 3.5 The Care Act 2014 requires that local authorities must involve any carer that the adult has when assessing the extent of that adult’s care and support needs (section 9(5)). The Act and the regulations make it clear that in deciding whether the adult is eligible for local authority support, the care provided by the carer must be ignored.³⁹
- 3.6 Even if the ‘adult needing care’ is ineligible for care and support, any carer they have is entitled to an assessment of their needs. If these needs are considered ‘eligible’ then the Act states that support services to meet these needs can be provided to the adult. Accordingly the assessment and eligibility processes for adults ‘in need’ and for carers are inextricably intertwined – and considered in greater detail below.

The promotion of ‘well-being’

- 3.7 The Act lacks a coherent set of guiding principles (of the kind found in the Mental Capacity Act 2005, section 1). Instead it contains a general duty to promote the ‘well-being’⁴⁰ of individuals (ie adults and carers). The duty applies to local authorities and their staff/members when exercising ‘any function’ under Part 1 of the Act (ie sections 1 - 80).
- 3.8 While the Act refrains from using the word ‘principle’ when referring to the ‘well-being’ duty, the statutory guidance shows no such reticence – describing it as such ‘because it is a guiding principle that puts wellbeing at the heart of care and support’ (para 1.2).
- 3.9 Section 1(2) of the Act provides a list of factors to which the duty ‘relates’, namely: personal dignity, physical and mental health and emotional well-being; protection from abuse and neglect; control over day-to-day life; participation in work, education, training or recreation; social and economic well-being; domestic, family and personal relationships; suitability of living accommodation; and ‘the individual’s contribution to society’. Notable omissions from this list are ‘choice’ and ‘independent living’ (but see para 3.12 below).
- 3.10 Section 1(3) states that when discharging any obligation under the Act, local authorities must ‘have regard to’—
- a) the importance of beginning with the assumption that the individual

³⁸ House of Commons Health Committee - Third Report Social Care 2010 conclusions para 9 and 18 and at www.publicationsparliament.uk/pa/cm200910/cmselect/cmhealth/22/2202.htm

³⁹ The Care and Support (Eligibility Criteria) Regulations 2014 regulation 3(3) and see the statutory guidance para 10.26 (considered below).

⁴⁰ In the Act it is a general duty ‘to promote that individual’s well-being’ (hyphenated) whereas the statutory guidance eschews the hyphen.

- is best-placed to judge the individual’s well-being;
- b) the individual’s views, wishes, feelings and beliefs;
- c) the need to prevent/delay the development of needs for care and support;
- d) the need to make decisions that are not based on stereotyping individuals;
- e) the importance of individual’s participating as fully as possible in relevant decisions (including provision to them of necessary information and support);
- f) the importance of achieving a ‘balance between the individual’s wellbeing and that of any friends or relatives who are involved in caring for the individual’;
- g) the need to protect people from abuse and neglect;
- h) the need to ensure that restrictions on individual rights/freedoms be kept to the minimum necessary.

3.11 Despite the obvious fear that these considerations are so broad and numerous that they could prove to be of limited value, this may not be the case – particularly in relation to the first factor namely: *(a) the importance of beginning with the assumption that the individual is best-placed to judge the individual’s well-being.* In many respects this requirement has similarities with the ‘presumption of capacity’ in the Mental Capacity Act 1983, section 1. This means, for example, that a carer’s or adult in need’s assessment as to what will best advance their ‘well-being’ must be assumed to be correct unless the authority has cogent evidence to rebut this presumption. The importance of this principle is perhaps best demonstrated when analysing the process of determining an individual’s eligibility for care and support and the arrangements appropriate to address eligible needs (see paras 4.9 and 5.27 below).

3.12 As noted above, a criticism of the ‘well-being’ obligation concerns the Act’s failure to include an explicit reference to the right to ‘independent living’ – i.e. as protected by Article 19 UN Convention on the Rights of Persons with Disabilities (CRPD). The guidance, however, goes a good way to addressing this omission, stating that (para 1.19):

The wellbeing principle is intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as independently as possible, for as long as possible, is a guiding principle of the Care Act.

3.13 Article 19 is concerned about the rights of disabled people to ‘full inclusion and participation in the community’ and the right to make choices about where they live and with whom they live. It envisages a range of community support services as a prerequisite to the maintenance of independence and the prevention of isolation and segregation of disabled people. Such an express statement in statutory guidance is of considerable value – and in many respects amounts to an entrenchment of Article 19 in domestic social care law. In the absence of such forceful endorsement, the courts and Ombudsmen have shown a surprising willingness to have regard to the

Convention in recent judgments/reports⁴¹ - and references to para 1.19 of the statutory guidance can be expected to be numerous.

⁴¹ See for example *Burnip v. Birmingham City Council* [2012] EWCA Civ 629 and *R (Bracking and others) v. Secretary of State for Work and Pensions* [2013] EWCA Civ 1345.

4. The rights of 'adults in need' – an overview

Assessments of 'adults in need'

- 4.1 If a carer is seeking assistance from the social services department, the first response will in general be for the 'person being cared for' to have an assessment of his or her needs for social care support services. If that person is not an adult, then the assessment will be under the Children Act and this process is considered at chapter 9 below.
- 4.2 Broadly speaking the assessment of 'an adult in need' has three key stages. The assessor (i.e. the social services employee – or possibly an independent/charity sector employee – see para 5.6) must:
- 1 Gather all relevant information concerning the adult'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, GPs, housing personnel etc.
 - 2 Decide which of the various requirements identified during the first stage meet the 'eligibility criteria' and so entitle the adult to care and support services.
 - 3 Construct a care and support plan to detail how these needs will be met by specified services or a direct payment (see para 6.18).
- 4.3 When undertaking such an assessment, social services must in almost all cases⁴² follow the statutory guidance issued by the Department of Health (the principal chapters being chapter 6 – 'Assessment and eligibility' and chapter 10 – 'Care and support planning'). Other guidance issued by (or endorsed by) the Department of Health must also be taken into consideration and followed. If a decision is taken to deviate from the guidance, cogent reasons explaining why should be provided – and the greater the departure, the more likely it is that the Court or Ombudsman would find such action impermissible.⁴³ 'Other guidance' that falls into this category includes the 2014 Act advice issued by the Social Care Institute of Excellence (SCIE) concerning 'assessment and eligibility'.⁴⁴

Stage 1 – data gathering

- 4.4 Section 9 of the Act stipulates that the duty to assess adults is triggered by the

⁴² Adults who have been detained for treatment under the Mental Health Act 1983 may be entitled to support services under section 117 of that Act as well as under the Care Act 2014. In almost all cases, the support that their carers may need will be provided under the Care Act 2014 (since services under section 117(2) must be provided 'for any patient' (so detained) it is unlikely that they could encompass support services provided for a carer). For more detailed analysis of section 117 services see – Luke Clements, *Community Care and the Law*, 6th edition (Legal Action Group, 2015).

⁴³ *R v Islington LBC ex p Rixon* (1998) 1 CCLR 119 at 123.

⁴⁴ Full title at www.scie.org.uk/care-act-2014/assessment-and-eligibility/ - There is no clarity as to the status of these resources but the web-based materials carry the Department of Health logo (as well as ADASS and the LGA logos)

'appearance of need' and arises regardless of the 'level' of those needs or the person's financial resources (i.e. it applies to self-funders). The assessment must have specific regard to the well-being duty and must involve the adult and any carer(s).

- 4.5 The statutory guidance gives useful emphasis to the need for assessors to be 'appropriately trained'. Para 6.86, for example, states that if an 'assessor does not have the knowledge of a particular condition or circumstance, they must consult someone who has relevant expertise' and at para 6.84 it requires that:

assessors undergo regular, up-to-date training on an ongoing basis. The training must be appropriate to the assessment, both the format of assessment and the condition(s) and circumstances of the person being assessed. They must also have the skills and knowledge to carry out an assessment of needs that relate to a specific condition or circumstances requiring expert insight, for example when assessing an individual who has autism, learning disabilities, mental health needs or dementia.

- 4.6 Section 10(7) of the 2014 Act requires that carers be involved in their assessment and the guidance requires that assessments be 'person-centred, involving the individual and any carer that the adult has, or any other person they might want involved' (para 6.9) and that they must 'establish the total extent of needs' (para 6.10). Local authorities are also required to 'provide in advance, and in accessible format, the list of questions to be covered in the assessment' (para 6.38).

- 4.7 The 'eligibility criteria' regulations⁴⁵ make explicit that the decision about whether an adult has eligible needs, is made on the basis that it does not take into account any support that is being provided by third parties (i.e. carers): 'instead, where a person receives support from a carer, this will be taken into account during the development of the care and support plan.'⁴⁶ This important point is addressed in the guidance, which at chapter 6 (Assessment and eligibility) states:

6.15 During the assessment, local authorities must consider all of the adult's care and support needs, regardless of any support being provided by a carer. Where the adult has a carer, information on the care that they are providing can be captured during assessment, but it must not influence the eligibility determination.

- 4.8 This approach is restated in the care and support planning section of the guidance (para 10.26) which requires that authorities 'must identify, during the assessment process, those needs which are being met by a carer at that time, and determine whether those needs would be eligible'.

- 4.9 Although there is a presumption that the adult is 'best placed to judge their wellbeing' (see para 3.11 above) – this can be displaced by evidence and the Act requires that any assessment of an adult in need must involve the adult's carer. It follows that if the adult is failing to provide an accurate account of

⁴⁵ The Care and Support (Eligibility Criteria) Regulations 2014, reg. 2(3) which states that 'an adult is to be regarded as being unable to achieve an outcome if the adult ... is unable to achieve it without assistance'.

⁴⁶ Department of Health *Draft national minimum eligibility threshold for adult care and support discussion document* June 2013 para 1.23.

their abilities, the carer or a third party is able to provide information that puts the record straight (see para 13.1 below).

- 4.10 Not infrequently the assessor will use standard questionnaires that could be criticised as overly simplistic/superficial and which fail to capture the extent of the adult's care and support needs. For this reason adults and their carers should bring to the assessment written information⁴⁷ that identifies the problems that the carer/adult are experiencing. These can then be given to the assessor to ensure that when the decision on eligibility is made – it takes account of this additional information (and if the information is not accepted, that reasons for rejecting the evidence are provided).

Stage 2 – the eligibility decision

- 4.11 Having obtained the relevant information about the adult's care and support needs the assessor must then determine whether these are 'eligible' needs. This is done by comparing the needs against the statutory eligibility criteria.⁴⁸ These, in essence require that because of the adult's illness/impairment they are unable to do two or more key activities (unable to 'achieve outcomes' is the way this is phrased) and that as a consequence this has a significant impact on their wellbeing.

- 4.12 The formal requirements are therefore that:

- a) the needs arise from a physical or mental impairment or illness;
- b) as a result the adult is unable to achieve two or more specified outcomes; and
- c) as a consequence, there is (or there is likely to be) a significant impact on their well-being.

- 4.13 In this process – a key word is 'significant' and it is one that also appears in the carers eligibility criteria (see below). The statutory guidance avoids a precise definition of what 'significant' means – but advises that:

Needs may affect different people differently, because what is important to the individual's wellbeing may not be the same in all cases. Circumstances which create a significant impact on the wellbeing of one individual may not have the same effect on another (para 6.108);

- 4.14 The specified 'outcomes' are listed in regulation 2(2) as being:

- a) managing and maintaining nutrition;
- b) maintaining personal hygiene;
- c) managing toilet needs;
- d) being appropriately clothed;
- e) being able to make use of the adult's home safely;
- f) maintaining a habitable home environment;
- g) developing and maintaining family or other personal relationships;
- h) accessing and engaging in work, training, education or volunteering;

⁴⁷ For example, copies of letters from people who have knowledge of the person's needs, abilities/inabilities and aspirations etc. – such as family members, friends, GPs, nurses, community or spiritual leaders and so on.

⁴⁸ Detailed in The Care and Support (Eligibility Criteria) Regulations 2015 SI 313, regulation 2.

- i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and
- j) carrying out any caring responsibilities the adult has for a child.

- 4.15 Para 6.103 of the guidance provides examples of how local authorities should consider each of the above outcomes – while emphasising that it does not constitute an exhaustive list of examples. These explain, for example that in considering the ability to manage/maintain nutrition, a relevant issue would be whether that adult is 'able to prepare ... food and drink'; that maintaining personal hygiene would include the ability to wash oneself and launder one's clothes; that managing toilet needs should include a consideration of the 'adult's ability to access and use a toilet and manage their toilet needs' and so on.
- 4.16 Importantly in relation to the outcome in regulation 2(2)(j) above – namely 'carrying out any caring responsibilities the adult has for a child' 2015 guidance⁴⁹ explains that this requires councils to consider the support disabled parents and carers may need in carrying out their responsibilities to care for a child - who may potentially be a young carer for the disabled adult. This is further considered at para 10.11 below.
- 4.17 Although there are ten relatively widely drawn 'specified outcomes' – there may be situations where an adult is assessed as ineligible due to being unable to achieve only one such outcome – notwithstanding that the consequence is severe. The ramifications of this problem will no doubt be resolved by litigation, but for the purposes of this guide – two important points need to be borne in mind. Firstly, that the local authority would have a 'power' to provide care and support to the adult in need in such a case⁵⁰ and secondly, that if the carer(s) of the adult is/are assessed as eligible for support (by reference to the carer's eligibility criteria) their support needs can be met by providing care services to the adult (see para 5.35 below).
- 4.18 The regulations (reg 3) defines 'unable' in expansive terms: a person is to be deemed 'unable' to achieve an outcome if he or she:
- a) is unable to achieve it without assistance;
 - b) is able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;
 - c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or
 - d) is able to achieve it without assistance but takes significantly longer than would normally be expected.
- 4.19 As noted above, the regulations and guidance are unequivocal concerning the input of carers: this must be ignored during the assessment process of the adult and during the determination of eligibility. As the guidance states (para 6.113):

The eligibility determination must be made based on the adult's needs and how these impact on their wellbeing. Authorities must only take consideration of whether the adult has a carer, or what needs may be met by a carer after the eligibility determination when a care and

⁴⁹ Department of Health (et al) *The Care Act and Whole-Family Approaches* (2015) p. 33.

⁵⁰ Section 19 Care Act 2014.

support plan is prepared. The determination must be based solely on the adult's needs and if an adult does have a carer, the care they are providing will be taken into account when considering whether the needs must be met.

Stage 3 – providing care and support to meet the eligible needs

4.20 The Care Act places a duty on local authorities to ensure that an adult's eligible needs are met by the provision of care and support services – which may include a direct payment. Since this is very similar to the duty owed to a carer who has been assessed as having eligible needs – this question is considered at para 5.44 below under the general heading of the 'care and support planning'.

4.21 An example of an assessment of an adult in need

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

Stage 2

The second stage of an assessment requires the assessor to make a decision about which of the needs identified in the first stage meet the eligibility criteria. In making this decision the care provided by Albert's wife is ignored.

Put very simply the social worker asks 'what will happen if the authority does not respond to the identified need' (e.g. help getting up, help with feeding and so on)?' What will the consequence be for Albert?

On this basis the assessor determines that Albert would (without assistance) be unable to feed himself; wash himself; manage his toilet needs; dress himself; be safe in his home; maintain a habitable home environment; maintain important relationships and access the local community – accordingly he would be unable to achieve all but two of the specified outcomes. The assessor also determines that the effect of being unable to achieve these outcomes would have a significant impact on Albert's wellbeing. Accordingly he is eligible for care and support and the local authority is under a duty to ensure this is provided.

Where a person has some needs that are eligible and some that

are not, the authority must provide information/advice on resources that could help address the needs which are not eligible (statutory guidance para 2.53).

Stage 3

The local authority must prepare a care and support plan that ensures that all of Albert's eligible needs are met. In general, it would only do this once it has undertaken a carer's assessment of Albert's wife's support needs. This assessment will, in essence, consider the sustainability of her caring role and identify which (if any) of Albert's care needs she is willing and/or able to meet. The local authority then draws up a 'care plan' which describes the services that it will provide to meet Albert's needs and also any of his wife's eligible 'carers' support needs.

The law also requires that they both be offered '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, they could be given the cash equivalent with which to buy the necessary support (direct payments are considered at para 6.18 below).

However, although carers' assessments will most commonly be undertaken at the same time as for the adult they look after, a carer's assessment is not conditional upon an assessment of the service user and the carer element of the above will need to be applied

- 4.22 Although the assessment process for a disabled child is similar in many respects to that of a disabled, elderly or ill adult's assessment – it is sufficiently different to warrant separate analysis. It is therefore considered at para 9.3 below.

5. The carer's assessment

The carer's assessment process – a nutshell/generalised overview

When an 'adult in need'⁵¹ is being assessed and their carer agrees to have a 'carer's assessment', the process should proceed as follows.

1. Information about the adult's needs (including their eligible needs) (see para 4.4 above) is gathered in their assessment.
2. The carer's needs (including their eligible needs) are identified in the carer's assessment process. This analyses, not only the sustainability of the caring role, but also whether the carer is willing and able to carry on caring and/or provide 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.
3. Once the assessor has completed the carer's assessment, s/he will then be in a position to decide what services should be provided to the adult in need and what services should be provided to the carer.
4. The assessor then draws up a care and support plan for the adult and if needs be a support plan for the carer which explain how their eligible needs will be met (i.e. by identifying the services the local authority will provide or the amount of the direct payment it will make). The carer and the adult in need will also be told of the cost the local authority incurs in meeting their needs – which is referred to as their 'personal budget'. If the needs are being met by way of a direct payment, the amount of the direct payment will be the same as the personal budget (see para 6.24 below).

Note

Although carers' assessments will most commonly be undertaken at the same time as an assessment of the adult 'in need', a carer's assessment is not conditional upon an assessment of the service user.

5.1 The Care Act (section 10) makes material changes to the current duty to assess carers' needs. The new duty to assess is triggered by the 'appearance of need' and is no longer dependent upon the carer making a request or dependent upon the carer providing (or intending to provide) regular/substantial care. There is a 'clear consensus' among local authorities that the 'costs related to carers – in terms of both assessments and associated services pose one of the greatest financial risks to the reforms'.⁵²

5.2 Although the principal carer assessment duty is only owed to adult carers

⁵¹ In general terms this 'nutshell overview' also applies to disabled children being assessed - but see para 9.3 below.

⁵² ADASS & LGA *Joint Response to the Care Act Regulations and Guidance Consultation* (August 2014) para 51.

caring for other adults – the Act contains specific provisions covering carers of disabled children and young carers who are in transition into adulthood (considered below at para 10.48 and 11.22). These are complemented by measures in the Children and Families Act 2014 which provide for significant new duties in relation to parent carers and young carers as well as enhanced obligations on local authorities to ‘identify any children who are involved in providing care’ (para 6.68 of the statutory guidance) – and these are considered separately below (see chapters 10 and 11 below).

Which social services department is responsible?

- 5.3 The Care Act is curiously vague on the process for identifying which local authority is responsible for undertaking a carer’s assessment.⁵³ Section 20(1) stipulates, however, that the local authority that is responsible for meeting a carer’s eligible needs is the one in which the adult needing care ‘is ordinarily resident in’.⁵⁴ The assumption therefore must be that the duty to undertake a carer’s assessment is the responsibility of the local authority that is responsible for the person for whom that carer cares.⁵⁵ It is understood that the Association of Directors of Adult Social Services (ADASS) is preparing a protocol on undertaking cross-border assessments to assist councils in making decisions about this.

Carers’ assessments – timescale

- 5.4 The Care Act (as with the previous legislation) does not stipulate a period within which a carer’s assessment must be commenced or indeed completed. Para 6.29 of the statutory guidance states that assessments:

should be carried out over an appropriate and reasonable timescale taking into account the urgency of needs and a consideration of any fluctuation in those needs. Local authorities should inform the individual of an indicative timescale over which their assessment will be conducted and keep the person informed throughout the assessment process.

- 5.5 Where a statute does not prescribe a time for the discharge of one of its requirements, the courts require that it be done ‘within a reasonable period’ and of course what this is, will depend upon the facts of any particular case. However, in relation to community care assessments 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’.⁵⁶ Given that a carer’s 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 carer’s assessment must also be undertaken well within the four to six week period.

⁵³ Or indeed the assessment of an adult in need.

⁵⁴ Or is present in its area but of no settled residence

⁵⁵ The pre-Care Act guidance also advised that disabled person’s home authority was responsible for the carer’s assessment and the provision of any ‘carer’s services’: Department of Health Practice guidance to the Carers and Disabled Children Act 2000, para 24-7.

⁵⁶ Local Government Ombudsman ‘Complaints about councils that conduct community care assessments’ (2011) Fact Sheet S4.

Delegation of assessments

- 5.6 Section 79 of the Care Act enables local authorities to delegate almost all of their functions under the Act.⁵⁷ Section 79(6) makes it clear that ultimate responsibility in such cases will still rest with the authority (any acts/omissions by the delegated body will be treated as done/omitted to be done by the local authority). In 2014, and in anticipation of these reforms, all English local authorities were given power to delegate virtually all of their adult social services powers.⁵⁸
- 5.7 Many local authorities have already delegated aspects of carers' assessments to local independent carer support groups. This was possible under the pre-Care Act legislation so long as the actual decision on the carer's eligibility for support was made/approved by the local authority: the theory being that the carers' group did the data gathering/discussions with the carer and the local authority then signed off their recommendations.⁵⁹ This arrangement can of course continue, but the local authority is now able to delegate the eligibility decision and 'sign-off'. Delegated arrangements of this kind would need to ensure that there is clarity about budgetary provision so that funds or services can be allocated in a way that enables all of a carer's eligible needs to be met. In addition, clarity would be required concerning the responsibility for identifying children in the household who may be young carers and the arrangements for discharging the duty to assess any young carers identified in this process (see para 10.11).
- 5.8 Local authorities have for many years been able to delegate carers' assessments to NHS partners in cases where they have entered into a formal partnership arrangement with the NHS body under s75 NHS Act 2006 (formerly s31 Health Act 2001). Where these arrangements are continued, these will need to be updated in the light of Care Act requirements and again there needs to be clarity about identification of young carers and undertaking a young carer's assessment.
- 5.9 Councils may also wish to consider how delegation of parts of carers' assessments aids taking a whole family approach (see para 10.23). This could particularly be an issue if there were to be separate assessments being undertaken by an Adult Services team (for the service user), a carers' centre (for the adult carer) and a young carers' service.

Carers' assessments – basic principles

- 5.10 Section 10 of the 2014 Act requires that carers' assessments must ascertain:
- whether the carer is able/willing to provide and continue to provide the care;
 - the impact on the carer's 'well-being';
 - the outcomes the carer wishes in day-to-day life;

⁵⁷ The exceptions include safeguarding (sections 42 – 47) and charging (section 14).

⁵⁸ The Contracting Out (Local Authorities Social Services Functions) (England) Order 2014 SI No. 829 made pursuant to the Deregulation and Contracting Out Act 1994 s70(2) and (4) and s77(1).

⁵⁹ The evidence suggests that local authorities were already delegating carers' assessments before the law permitted this – see W Mitchell 'How local authorities allocate resources to carers through carer personal budgets' (2014) Research Findings, NIHR School For Social Care Research, London

- whether the carer works or wishes to (and/or) to participate in education, training or recreation.

Willing and able

- 5.11 The ‘carer blind’ element to the new regime (see para 4.7 and 5.49) is perhaps the most important new ‘explicit’ dimension to the statutory guidance and one that is mentioned repeatedly.
- 5.12 At law it is arguable that assessments have always had to take this approach, since there is no requirement at law that adults provide care for other adults (this aspect of the liable family rule was repealed in 1948⁶⁰). Section 10(5) requires that assessments must take into account the extent to which the carer is ‘willing, and is likely to continue to be willing’ to provide care. The guidance at para 2.49 that authorities ‘should not assume that others are willing or able to take up caring roles’ echoes earlier guidance – for example the original 1990 policy guidance to the Community Care reforms⁶¹ and guidance to the Carers (Recognition & Services) Act 1995.⁶²

The right to a private assessment

- 5.13 As with the pre-Care Act guidance, emphasis is given to the importance of carers having the opportunity to have their assessments in private – i.e. away from the ‘adult in need’, where the carer so chooses.⁶³ At para 6.40 authorities are required to consider the ‘preferences of the individual with regards to the timing, location and medium of the assessment’ and at para 6.18 ‘where appropriate’ carers’ ‘views should be sought in a separate conversation independent from the adult’s needs assessment’. The Act, and guidance, provide for assessments to be ‘combined’ but this can only be with consent: section 12(5) stating ‘only if the adult to whom the needs or carer’s assessment relates agrees’ – a point emphasised at para 6.72 of the guidance – namely that if ‘either of the individuals concerned does not agree to a combined assessment, then the assessments must be carried out separately’. Even where assessments are combined, 2015 guidance,⁶⁴ stresses the importance ‘that each individual, including any children, has a chance to have a private conversation with the assessor in case there are areas they wish to identify and explore separately’.
- 5.14 In relation to young carers there is a move (considered below see para 10.23) to use ‘whole family’ assessments. While this may work for some young carers – this will not always be the case and it is clear from the legislation, that combined assessments are an option that cannot be imposed by the authorities. The danger, of course, is that such an approach

⁶⁰ National Assistance Act 1948, section 1: see generally Luke Clements ‘Does your carer take sugar?’ Washington and Lee Journal of Civil Rights and Social Justice: (2013) pp397 – 434.

⁶¹ *Community Care in the Next Decade and Beyond* (HMSO 1990) para 3.28.

⁶² Department of Health *Carers (Recognition & Services) Act 1995 Practice Guidance* LAC (96)7 at para 9.8; WOC 16/96 and WHC (96)21 in Wales (also at para 9.8).

⁶³ See for example, Practice Guidance LAC (96)7 and WOC 16/96 and WHC (96)21 in Wales – para 9.1 and *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.

⁶⁴ Department of Health (et al) *The Care Act and Whole-Family Approaches* (2015) at p. 15.

can result in a 'rounding down': compromising personal ambitions in the stir of family complexities. Carers' difficulties in accessing their right to a separate assessment are well documented – parent carers and young carers particularly⁶⁵ – and the explicit statutory recognition of their right to a separate assessment is of importance.⁶⁶

The nature and setting of the assessment

- 5.15 The statutory guidance advises that to enable individuals to prepare for their assessment, they should be provided in advance (in an accessible format) with the list of questions to be covered in the assessment (para 6.38). At the same time the authority must consider if the individual may have 'substantial difficulty' in being involved in the assessment process and, if so, consider the need for independent advocacy (para 6.23: the advocacy requirements are considered below). At the conclusion of the assessment the local authority must 'ensure that it is an accurate and complete reflection of the person's needs' (para 6.46) – which must presumably mean sharing a draft and getting it agreed (or details of what is not agreed) – since a copy of the assessment must then be given to the carer/adult in need (para 6.96).⁶⁷ The duty to endeavour to reach agreement at this stage is not however explicit – unlike the requirement in para 10.83, that authorities 'must take all reasonable steps to reach agreement with the person for whom the plan is being prepared'.⁶⁸
- 5.16 Individuals must be 'at the heart' of their assessments and in the case of an adult 'in need' the authority 'must also involve any carer the person has (which may be more than one carer)'.⁶⁹
- 5.17 Carers' assessments must seek to establish not only the carer's needs for support, but 'also the sustainability of the caring role ... [i.e.] the carer's potential future needs for support' (6.18). They must specifically consider the carer's 'desire and ability to work and to partake in education, training or recreational activities, such as having time to themselves' and the carers' wishes in this respect should be considered over the short and longer term (section 10(6) and para 6.19 of the guidance).
- 5.18 Assessments should be 'proportionate'⁷⁰ ('light touch' or detailed depending on the extent of need) – but the guidance advises that even if done quickly, people should not be 'removed' from the 'process too early' (para 6.25). However, as noted above, the guidance recognises that assessments may 'where appropriate' be carried out over the phone or online although requiring that authorities consider whether in doing so this 'poses any challenges or risks for certain groups, particularly when assuring itself that

⁶⁵ See for example, Luke Clements *Carers and their Rights* 5th ed (Carers UK 2012) paras 10.4 – 10.6 and 11.3 – 11.4.

⁶⁶ The practice guidance to the Carers & Disabled Children Act 2000 advised that in order that the carer have an opportunity to opt for a confidential meeting, the assessor should endeavour to make arrangements for the assessment 'over the phone, and away from the home or while the cared for person is out' – see Department of Health 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' para 3.11.1.

⁶⁷ The Care and Support (Assessment) Regulations 2014 reg 3(1)

⁶⁸ An almost identical to obligation to that in the Community Care Assessment Directions 2004 (Direction 2).

⁶⁹ Section 9(5) and para 6.30 of the guidance.

⁷⁰ The Care and Support (Assessment) Regulations 2014 reg 3(1)

it has fulfilled its duties around safeguarding, independent advocacy, and assessing mental capacity' (para 6.28) – and presumably satisfying its duty to ascertain if there are carers involved – so they can be contacted and offered an assessment. Every assessment must also 'identify any children who are involved in providing care' so that 'where appropriate ... the child or young carer' is referred for an assessment (para 6.68 – see young carers discussion below).

Advocacy support

- 5.19 The Act, its regulations and statutory guidance⁷¹ make specific provision for advocates to be provided where a person has 'substantial difficulty' in being actively involved with the planning process (and there are no suitable family or friends able to fulfil this role). Less is said concerning the needs of those who don't have such a difficulty – but nevertheless feel the need for support from friends or advocates. The pre-Care Act guidance addressed this need directly – requiring authorities to make carers aware that they could have a friend or advocate present at their assessment.⁷²
- 5.20 The duty must, nevertheless, remain under the 2014 Act. Section 10(7) obliges local authorities, when carrying out a carer's assessment, to 'involve' (among others) 'any person whom the carer asks the authority to involve'. Para 6.31 of the Act guidance requires that authorities identify adults who are unable to 'effectively engage in the assessment process independently' and to seek to 'involve somebody who can assist' – and the well-being duty (section 1(3)(e)) highlights the importance of individuals 'participating as fully as possible' in these processes and of the need to be provided with the 'support necessary' to enable them to participate.

Carer eligibility criteria

- 5.21 Where an assessment identifies that a carer has support needs (as with adults 'in need' – see para 4.11 above) then the authority must decide if these needs are sufficient to meet the eligibility criteria.
- 5.22 The eligibility criteria for carers (put broadly) measure whether as a consequence of providing care, the carer is unable to undertake certain key roles/tasks (i.e. household activities/other caring responsibilities/employment/education/recreation) or that their health is at significant risk.
- 5.23 As with the eligibility criteria for 'adults in need' (see para 4.12 above) the carer eligibility criteria contain three basic criteria, namely⁷³ that:
- a) The needs arise as a consequence of providing necessary care for an adult;
 - b) The effect of the carer's needs is that any of the circumstances specified below apply to the carer;
 - c) As a consequence there is, or is likely to be, a significant impact on

⁷¹ Section 67 of the Act; The Care and Support (Independent Advocacy Support) Regulations 2014 chapter 7 of the statutory guidance.

⁷² Department of Health *Carers and Disabled Children Act 2000: Practice Guidance* (DH 2000) para 60.

⁷³ Regulation 3 of the Care and Support (Eligibility Criteria) Regulations 2014.

the carer's well-being.

- 5.24 Unlike the criteria for 'adults in need' there is no need for 'two or more circumstances/outcomes' – 'any' one is potentially sufficient to trigger eligibility.

Significant impact

- 5.25 As with the criteria for 'adults in need' (see para 4.13 above) a key word is 'significant' – which (again) is not defined by the regulations or the statutory guidance although it does advise (at para 6.124) that significant is – on one level an essentially subjective concept, that:

the impact of needs may affect different carers differently, because what is important to the individual's wellbeing may not be the same in all cases. Circumstances which create a significant impact on the wellbeing of one individual may not have the same effect on another.

- 5.26 A potential problem with the requirement that the impact be on the 'carer's wellbeing', concerns consequential impacts on third parties. For example, when a carer is coping with her heavy caring load for her parent but the adverse impact manifests itself in consequential symptoms evident in her children or another dependent adult. In such a case the need for replacement care (see para 6.5 below) will be obvious and essential – the problem will be how to demonstrate that this triggers eligibility. This could be established either (1) as evidence that she is 'unable to achieve' her 'caring responsibilities ... for a child' or to care for 'other persons' for whom she cares (regulations 3(2)(b) (ii) and (iii) respectively⁷⁴ - see below) or (2) by reference to the definition of wellbeing in section 1 of the 2014 Act (see para 3.7 above). Wellbeing is not a purely egotistical concept – it relates also to (for example) 'domestic, family and personal relationships (section 1(2)(g)) and requires consideration of 'the importance of achieving a balance between the individual's wellbeing and that of any friends or relatives who are involved in caring for the individual' (section 1(2) (f)).
- 5.27 Ultimately the decision as to whether an impact is 'significant' will be for the local authority to make. In so determining, it must start from the 'assumption that the individual is best-placed to judge' their well-being (see paras 3.11 above) and if the local authority disagrees with the individual's assessment on this question the authority would be expected to provide cogent evidence to explain its reasoning.
- 5.28 Where there is independent evidence from a health or other professional – for example from an occupational therapist that the carer is suffering depression or at significant risk of harm, or from an employer/HR manager that without support the carer may have to give up work or go part-time – then clearly this is 'significant' and it would be difficult for a local authority to disagree with this analysis, unless it had evidence of a similar expertise to the contrary.

⁷⁴ The Care and Support (Eligibility Criteria) Regulations 2014.

Necessary care

- 5.29 The criteria also require that the care provided is 'necessary care'. The statutory guidance indicates that this requirement has been included solely to deal with cases where the adult is capable of meeting the need his or herself (para 6.117) and this of course begs the question as to who is to be the judge of this. As noted above (para 3.11 above) the Act creates an assumption that the 'individual is best-placed to judge the individual's well-being' (section 1(3)). It would appear to follow from this, that in determining whether care is 'necessary' the authority must start from the assumption that the individual's assessment is correct and if it takes a different view on what is 'necessary' it is required to adduce evidence/reasons to rebut this presumption.

Specified circumstances

- 5.30 The circumstances specified in (b) above are as follows—
- a) the carer's physical or mental health is, or is at risk of, deteriorating;
 - b) the carer is unable to achieve any of the following outcomes:
 - i. carrying out any caring responsibilities the carer has for a child;
 - ii. providing care to other persons for whom the carer provides care;
 - iii. maintaining a habitable home environment in the carer's home (whether or not this is also the home of the adult needing care);
 - iv. managing and maintaining nutrition;
 - v. developing and maintaining family or other personal relationships;
 - vi. engaging in work, training, education or volunteering;
 - vii. making use of necessary facilities or services in the local community, including recreational facilities or services; and
 - viii. engaging in recreational activities.
- 5.31 Any one of these specified circumstances, if they arise out of the caring role and have a significant impact, make the carer eligible for support.
- 5.32 The following section considers each of these specified circumstances and the text in italics (where it exists) is the additional commentary provided in the statutory guidance at para 6.128.

The carer's physical or mental health is, or is at risk of, deteriorating

- Over half of all carers have a caring-related health condition⁷⁵ and are twice as likely to be in bad health as non-carers.⁷⁶ The GP Patient Survey 2014 found that carers across all age groups are more likely to say they suffer from anxiety or depression.⁷⁷
- NHS England cites research findings that 84% of carers reported that caring had had a negative impact on their health and

⁷⁵ The Health and Social Care Information Centre (2010) *Survey of Carers in Households 2009/10* and see also Carers UK, *Missed Opportunities: the impact of new rights for carers*, June 2003.

⁷⁶ Carers UK *State of Caring Survey 2014* (a survey of 5,000 carers).

⁷⁷ NHS England, *GP Patient Survey 2014*

separate research that found a 23% increased risk of stroke for spousal carers.⁷⁸

- The Department of Health refers to the strain of caring and the serious impact on mental well-being with 73% of carers surveyed reporting increased anxiety; 82% increased stress since taking on their caring role; and half of carers surveyed stated they were affected by depression after taking on a caring role.⁷⁹
- There is 'strong evidence that parents (especially mothers) of children with developmental disability are at increased risk for stress and mental health problems compared to parents who do not have a child with developmental disability'.⁸⁰

Carrying out any caring responsibilities the carer has for a child

Any parenting or other caring responsibilities the carer has for a child in addition to their caring role for the adult e.g. the carer might be a grandparent with caring responsibilities for their grandchildren while the grandchildren's parents are at work.

The statutory guidance provides an example of such a circumstance (explored in further detail below – para 5.54)

Providing care to other persons for whom the carer provides care

Any additional caring responsibilities the carer may have for other adults, e.g. a carer may also have caring responsibilities for a parent in addition to caring for the adult with care and support needs.

Maintaining a habitable home environment

Whether the condition of the carer's home is safe and an appropriate environment to live in and whether it presents a significant risk to the carer's wellbeing. A habitable home should be safe and have essential amenities such as water, electricity and gas.

- Carers UK's 2014 *State of Caring* report found that 54% of carers are struggling to pay household bills.⁸¹
- Carers UK's 2014 *Caring & Family Finances Inquiry* found that 44% of carers were in debt because of their caring roles (a figure that rose to 69% when the family had no savings when they started to care).⁸² A third were unable to afford their utility bills and three quarters had cut back on holidays, leisure activities, buying clothes and going out with friends and family.

⁷⁸ NHS England *Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers* (2014)

⁷⁹ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015).

⁸⁰ Richard Hastings, *Children and adolescents who are the siblings of children with intellectual disabilities or autism: Research evidence* at citing a Position Paper of the Families Special Interest Research Group (2012).

⁸¹ Carers UK, *The State of Caring 2014* (involving 5,000 carers)

⁸² Carers UK, *Caring & Family Finances Inquiry* (2014)

Managing and maintaining nutrition

Whether the carer has the time to do essential shopping and to prepare meals for themselves and their family.

- 2014 research undertaken by Contact a Family, which found that due to financial difficulties, 31% went without food.⁸³
- The Department of Health⁸⁴ refers to evidence that 45% of carers had reported that as a result of caring they found it hard to maintain a balanced diet.

Developing and maintaining family or other significant personal relationships

Whether the carer is in a position where their caring role prevents them from maintaining key relationships with family and friends or from developing new relationships where the carer does not already have other personal relationships.

- A 2015 Carers UK report⁸⁵ found that 57% lost touch with friends or family as a result of caring and that eight in ten carers (83%) have felt lonely or socially isolated. 49% of carers have said that they have experienced difficulties in their relationship with their partner because of their caring role.
- The evidence suggests that the subjective feeling of loneliness and social isolation increases the risk of premature death by 26% and 29% respectively.⁸⁶

Engaging in work, training, education or volunteering

Whether the carer can continue in their job, and contribute to society, apply themselves in education, volunteer to support civil society or have the opportunity to get a job, if they are not in employment.

- A 2014 Carers UK report of working carers found that nearly half had reduced their hours and nearly a third (32%) had refused a promotion or taken a less qualified job in order to manage their workload and caring responsibilities;⁸⁷
- A joint report by the Department of Health and Employer for Carers found that 2.3 million people had quit work to care and almost 3 million have reduced their working hours.⁸⁸ Of those who gave up work, retired early or reduced working hours, 65% said it was the stress of juggling work and care was a contributing factor, 30% cited the lack of suitable care services and 22% cited

⁸³ Contact a Family, *Counting the Costs* (2014)

⁸⁴ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015).

⁸⁵ Carers UK State of Caring Survey 2014 (a survey of 5,000 carers).

⁸⁶ J Holt-Lunstad et al, 'Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review' in *Perspectives on Psychological Science* March 2015 vol. 10 no. 2 227-237 (meta-analysis of 70 independent research studies since 1980 written in English)

⁸⁷ Carers UK State of Caring Survey 2014 (a survey of 5,000 carers).

⁸⁸ Employers for Carers, Department of Health and Carers UK, *Supporting Working Carers: The Benefits to Families, Business and the Economy* (2013)

the expense of care services.⁸⁹

Making use of necessary facilities or services in the local community

Whether the carer has an opportunity to make use of the local community's services and facilities and for example consider whether the carer has time to use recreational facilities such as gyms or swimming pools.

- The Department of Health refers to evidence that 58% of carers said that they have reduced the amount of exercise they do since they started caring.⁹⁰

Engaging in recreational activities

Whether the carer has leisure time, which might for example be some free time to read or engage in a hobby.

- 2014 research undertaken by Contact a Family, which found that due to financial difficulties, 84% of carers went without leisure and days out.⁹¹

Unable to achieve an outcome

5.33 The Eligibility Criteria regulations (reg 3(3)) state that a carer is to be regarded as being unable to achieve an outcome, if: (a) is unable to achieve it without assistance; (b) is able to achieve it without assistance but doing so causes the carer significant pain, distress or anxiety; or (c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the carer, or of others.

5.34 The statutory guidance (para 6.119) gives various examples of what this may mean, including:

- *A carer might for example be able to care for the adult and undertake full-time employment, but if doing both, causes the carer significant distress, the carer should not be considered able to engage in employment.*
- *A carer might for example be able to provide care for their family and deliver necessary care for the adult, but, where this endangers the adult with care and support needs, for example, because the adult receiving care would have to be left alone while other responsibilities are met, the carer should not be considered able to meet the outcome of caring for their family.*

Carer eligible vs 'adult in need' ineligible

5.35 The statutory guidance makes clear that a carer's eligibility does not depend on whether the 'adult for whom they care has eligible needs' (para 6.116).

⁸⁹ Carers UK *State of Caring Survey 2015* (a survey of 4,500 carers).

⁹⁰ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015).

⁹¹ Contact a Family, *Counting the Costs* (2014).

Accordingly the fact that an adult is not eligible for support is irrelevant in so far as the carer's assessment is concerned. This obligation stems from section 20(7) of the Act, which states:

A local authority may meet some or all of a carer's needs for support in a way which involves the provision of care and support to the adult needing care, even if the authority would not be required to meet the adult's needs for care and support under section 18.

- 5.36 Such a situation is likely to arise in many contexts. A carer may be experiencing a significant impact due to caring for more than one person, even if the adults they 'care for' are not eligible when viewed in isolation. Even if only caring for one adult, that adult may only have one 'outcome' that they are unable to achieve (see para 4.12 above); or they may be refusing to be assessed etc. In such a case the local authority, if it assesses the carer as eligible, could nevertheless provide (for example) a sitting service that enabled the carer to have a break. As noted below, in such a case (see para 5.56 below) the carer could (for example) request a direct payment, and use that to commission their own replacement care from an agency (para 11.44 of the statutory guidance).
- 5.37 As the statutory guidance notes, if replacement care of this type is charged for 'then it would be the adult needing care that would pay, not the carer, because they are the direct recipient of the service' (para 11.45).
- 5.38 The obligation to meet a carer's eligible needs – even if the adult is ineligible – is reinforced by section 20(8) which provides that:
- Where a local authority is required ... to meet some or all of a carer's needs for support but it does not prove feasible for it to do so by providing care and support to the adult needing care, it must, so far as it is feasible to do so, identify some other way in which to do so.*
- 5.39 This, again, is of great potential value and is considered further in chapter 13. Such a situation could arise, for example, where the carer needs a break but the adult is refusing to have a sitting service that would enable the carer to have a break. In such a case the local authority cannot 'walk away' or close the file: it must continue to work with the adult in need and carer in order to find a resolution: 'some other way' of supporting the carer.

Funding panels

- 5.40 Many local authorities use 'panels' of various types (sometimes termed 'allocation panels', 'funding panels' or 'purchasing panels') as a means of rationing services. The legality of the way that some of these panels operate is open to question – creating as they do, an additional non-statutory hurdle for people in need and their carers.⁹² The 2014 Act makes no change to this situation and so the concerns raised by the courts and the Joint Committee on Human Rights concerning the legality of such 'panels' overruling social work recommendations will remain relevant.⁹³ The Local Government Ombudsman

⁹² For a general discussion on panels – see Luke Clements and Pauline Thompson *Community Care & the Law*, para 3.188 (5th edn, Legal Action Group 2011) the relevant extract being 'Allocation and funding panels'.

⁹³ For a detailed commentary on these decisions/reports see Luke Clements and Pauline Thompson *Community Care & the Law*, (5th edn, Legal Action Group 2011) para 3.188 – 3.191.

has also expressed similar misgivings. In a 2005 report, for example, he held that where an assessment has been carried out, a purchasing panel (and by implication a manager) cannot override the judgment of the assessor without providing clear reasons for doing so.⁹⁴ In relation to the use of panels, the guidance comments (at para 10.85):

Due regard should be taken to the use of approval panels in both the timeliness and bureaucracy of the planning and sign-off process. In some cases, panels may be an appropriate governance mechanism to sign-off large or unique personal budget allocations and/or plans. Where used, panels should be appropriately skilled and trained, and local authorities should refrain from creating or using panels that seek to amend planning decisions, micro-manage the planning process or are in place purely for financial reasons.

Duty to provide care & support for carers

- 5.41 Section 20 creates a duty to meet the assessed needs of carers and is, the Government states, 'the first ever legal entitlement to public support, putting them on the same footing as the people for whom they care.'⁹⁵ The duty rests with the local authority responsible for the adult in need and extends to self-funders (i.e. carers with assets above the new maximum limits) who request help.
- 5.42 Section 20 states that the duty is triggered when the local authority determines that the carer has eligible needs and either:
- a) if the local authority decides to meet the carer's needs by providing the carer with support:
 - i. there is no charge to the carer or if there is – the carer's financial resources are at or below the financial limit;⁹⁶ or
 - ii. there is a charge and the carer's financial resources are above the financial limit, but the carer nonetheless asks the authority to meet the needs in question.
 - b) if the local authority decides to meet the carer's needs by providing the adult in need with care and support:
 - i. there is no charge to the adult or if there is – the adult's financial resources are at or below the financial limit; or
 - ii. there is a charge and the adult's financial resources are above the financial limit, but the adult nonetheless asks the authority to meet the needs in question.

⁹⁴ LG Ombudsman Complaint no 04/A/10159 against Southend on Sea BC, 1 September 2005. The decision concerned a matter in which a plan drafted by a social worker following a detailed assessment was rejected by the local authority's care purchasing panel on the advice of the social worker's manager with limited knowledge of the service user. The Ombudsman stated: 'Having correctly prepared a detailed assessment in accordance with the statutory guidance, it was wrong for the council to dismiss all the information gathered in that process, and make a decision on the basis of [the acting manager]'s assurance. The decision flew in the face of the assessment'.

⁹⁵ Department of Health *The Care Bill explained: Including a response to consultation and pre-legislative scrutiny on the Draft Care and Support Bill* Cm 8627 (The Stationery Office 2013) para 73.

⁹⁶ Since almost all local authorities impose no charges on carers – this will almost invariably be the case where the local authority has decided to meet the need by providing the carer with support.

Care and support planning

5.43 The assessment process considered above, involves identifying 'needs' and then determining which of these (if any) are 'eligible needs'. This stage is then followed by the development of a care and support plan that explains how the eligible needs will be met. These stages are two sides of an equation: on one side there are the eligible needs that have to be met and on the other are the details of how this will be done. In order that the individual can determine whether their assessed needs are fully addressed in the care plan, the statutory guidance requires that they 'must be given a record of their needs or carer's assessment' (para 6.96)⁹⁷ and also their final care plan (para 10.87).

Care and support planning – principles

5.44 Section 25 details what must be in every care and support plan⁹⁸ (i.e. for a carer or an adult 'in need') and this duty is analysed in the statutory guidance (para 10.36). The requirements include:

- the needs identified by the assessment;
- whether, and to what extent, the needs meet the eligibility criteria;
- the needs that the authority is going to meet, and how it intends to do so;
- for a person needing care, for which of the desired outcomes care and support could be relevant;
- for a carer, the outcomes the carer wishes to achieve, and their wishes around providing care, work, education and recreation where support could be relevant;
- the personal budget ...;
- information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future;
- where needs are being met via a direct payment ... the needs to be met via the direct payment and the amount and frequency of the payments.

5.45 In *R (J) v Caerphilly CBC*⁹⁹ it was held that care plans must 'set out the operational objectives with sufficient detail – including detail of the 'how, who, what and when' – to enable the care plan itself to be used as a means of checking whether or not those objectives are being met'. A 2014 Ombudsman's report held (in similar terms) that an assessment must be more than merely a descriptive document: it must spell out with precision what the needs are, what the impact of the disability is on the carer(s) and whether the disabled person and the carers' needs can be met and can continue to be met into the future. The assessment must result in a care plan that identifies the needs, what is to be done about these needs, by

⁹⁷ Even if it is decided that none of their needs are eligible needs, the authority must nevertheless provide them with 'information and advice in an accessible form, about what can be done to prevent, delay, or reduce development of their needs' (para 2.52).

⁹⁸ Unless excluded by the Care and Support (Personal Budget Exclusion of Costs) Regulations 2014 – which concerns the exclusion of costs associated with the provision of intermediate care (including reablement support) services.

⁹⁹ [2005] EWHC 586 (Admin); (2005) 8 CCLR 255.

whom and when. If a direct payment is made, it must specify precisely what need these payments are intended to meet, why this level of payment is considered appropriate, or what outcome this will result in.¹⁰⁰

- 5.46 The most significant difference under the new regime is that every such plan for an 'adult' must have a 'personal budget' (s25 (1)(e) – discussed below). Since most local authorities already do this – it will probably make little practical difference.
- 5.47 The guidance requires that the person being assessed must be 'genuinely involved and influential throughout the planning process' and that: 'it should be made clear that the plan 'belongs' to the person it is intended for, with the local authority's role to ensure the production and sign-off of the plan to ensure that it is appropriate to meet the identified needs' (para 10.2). The care and support plan 'must take into consideration the individual's preferences' (para 10.20) and may include helping the person to access some disability-related benefits and allowances (para 10.24).
- 5.48 Of considerable importance to people whose needs could be met by various bodies – i.e. young people for whom education have responsibilities or people who have chosen not to seek a particular social security benefit, the guidance states (para 10.25):

The duty to meet eligible needs is not discharged just because a person has another entitlement to a different service which could meet those needs, but which they are not availing themselves of. The needs remain 'unmet' (and so the local authority under a duty to meet them) until those needs are actually met by the relevant service bring provided or arranged.

Carer input into adults 'in need' care plan

- 5.49 In relation to support provided by a carer – the statutory guidance repeats its recurring theme, that assessments are 'carer blind'. Para 10.26 stating:
- Local authorities are not under a duty to meet any needs that are being met by a carer... any eligible needs met by a carer are not required to be met by the local authority, for so long as the carer continues to do so. The local authority should record in the care and support plan which needs are being met by a carer, and should consider putting in place plans to respond to any breakdown in the caring relationship.*
- 5.50 In preparing a care/support plan, section 25(3) requires that local authorities must involve (among others) the adult for whom it is being prepared; 'any carer that the adult has', and 'any person who appears to the authority to be interested in the adult's welfare'. In relation to carers, the requirement is to involve the carer for whom it is being prepared, 'the adult needing care, if the carer asks the authority to do so' and any other person whom the carer asks (section 25(4)).
- 5.51 In the same vein, para 10.40 states that where a person with eligible needs is having these met by a carer at the time the plan is developed, the 'carer must be involved in the planning process' and the authority 'should record

¹⁰⁰ Local Government Ombudsman complaint number 13 002 982 against Birmingham City Council 12th March 2014.

the carer's willingness to provide care and the extent of this in the plan ... so that the authority is able to respond to any changes in circumstances ... more effectively'. Para 10.40 also provides that:

where the carer also has eligible needs, the local authority should consider combining the plans of the adult requiring care and the carer, if all parties agree, and establish if the carer requires an independent advocate.

Carers' services: respite/short breaks/replacement care

5.52 As noted above, the result of a carer's assessment will often be that the care and support plan for the adult 'in need' or a third party is adapted/changed to enable the carer to achieve the outcomes they consider to be of importance.

5.53 The Act and statutory guidance re-emphasises the legal position – that 'respite/short break care' is (where it consists of a service delivered to the adult 'in need' - for example as a sitting service or placement in a residential setting etc.) a care and support arrangement for the adult in need and not for the carer. A 2000 Department of Health note explained this well:¹⁰¹

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.

5.54 In some situations this process (addressing carer's eligible needs in the care and support plans of others) can raise issues that may be less common. One such example is given in the statutory guidance after para 11.38 and it concerns Divya, who is caring for her dying father and for her young children. Her father has a care package in addition, but Divya's carer's assessment identifies her as eligible for support due to her additional childcare responsibilities.¹⁰² The support plan that is developed for her consists of a carer's direct payment 'which she uses for her children to attend summer play schemes so that she get some free time to meet with friends and socialise when the family member provides care to her father'.

5.55 The guidance refers to support that involves the local authorities meeting a carer's needs by providing a service directly to the adult needing care as replacement care which:

may be needed to enable a carer to look after their own health and wellbeing alongside caring responsibilities, and to take a break from caring ... it should be considered a service provided to the cared-for person, and thus must be charged to them, not the carer (para 11.39).

¹⁰¹ Department of Health *Questions and Answers* – a note that accompanied the enactment of the 2000 Act; (the Answer to Question 7 'Are short term breaks (respite care) a service for carers or cared for people?')

¹⁰² By virtue of The Care and Support (Eligibility Criteria) Regulations 2014 Reg (3)(2)(b)(i).

- 5.56 Of importance is the statement (para 11.45) that if the local authority have a policy of charging for a particular type of replacement care 'then it would be the adult needing care that would pay, not the carer, because they are the direct recipient of the service'. This will also be the case where a carer is assessed as eligible for support but the adult being cared for does not have eligible needs – and accordingly 'does not have their own personal budget or care plan' (para 11.42). In such cases the carer could (for example) request a direct payment, and use that to commission their own replacement care from an agency (para 11.44).

Carers support services generally

Preventative services

- 5.57 Research suggests that funding carer support services is a cost effective preventative investment – that for every £1.00 invested in carers, there is a potential equivalent reduction in local authority cost of £5.90¹⁰³ and with significantly greater 'social return' benefits.¹⁰⁴
- 5.58 Section 2 of the Care Act requires local authorities to provide a range of support services that will prevent or delay the development of needs by carers and adults and in so doing the section stresses the 'importance of identifying carers... with needs for support which are not being met'.
- 5.59 There are, in effect, two 'preventative' duties on local authorities: a general (strategic) duty to have available services that help prevent or delay the development of 'needs' for care/support by individuals; and a specific duty when a carer or adult with needs comes to their notice – a duty to personalise the care/support that is provided and in so doing, to help remove or at least delay those 'needs' from increasing. In this context, the statutory guidance warns that 'should not... remove people from the process too early' (para 6.25) that:

From their very first contact with the local authority, the person must be given as much information as possible about the assessment process, as early as possible, to ensure a personalised approach to the assessment (para 6.22).

- 5.60 It follows that authorities cannot therefore use the existence of 'preventative services' as a reason for declining to find eligibility – to restrict access to personalised support programmes – a point addressed in 2015 guidance:¹⁰⁵

the duty to prevent carers from developing needs for support is distinct from the duty to meet their eligible needs. Local authorities cannot fulfil their universal prevention duty in relation to carers simply by meeting eligible needs, and nor would universal preventative services always be an appropriate way of meeting carers' eligible needs.

- 5.61 The guidance (para 2.50) gives young carers as an example of where

¹⁰³ Department of Health (et al.) *Economic Case for Local Investment in Carer Support* (2015)

¹⁰⁴ Baker Tilly (June 2011), *Social Return on Investment in support for carers*, The Princess Royal Trust for Carers: using a 'Social Return on Investment' methodology which considers a range of associated factors such as future tax receipts from carers enabled to return to work) - which found that a £5 million investment in carer support services produced approximately £73 million of value to society.

¹⁰⁵ Department of Health (et al.) *The Care Act and Whole-Family Approaches* (2015) p. 22.

specific preventative services are required – that where a local authority becomes aware that a child is carrying out a caring role ‘it should consider how supporting the adult with needs for care and support can prevent the young carer from under taking excessive or inappropriate care and support responsibilities’.

The relevance of local authority financial difficulties

- 5.62 Para 10.27 of the statutory guidance makes clear that the current law concerning the relevance of a local authority’s financial position remains (as first detailed in the *Gloucestershire* judgment¹⁰⁶) namely that although authorities can ‘take into reasonable consideration’ of their finances, they ‘must comply’ with their legal obligations. A local authority’s finances are relevant when it decides *how* to meet the eligible needs of an individual ‘but not *whether* those needs are met’. The guidance goes on to stress that authorities ‘should not set arbitrary upper limits on the costs [they are] willing to pay to meet needs through certain routes’ – although they may:

take decisions on a case-by-case basis which weigh up the total costs of different potential options for meeting needs, and include the cost as a relevant factor in deciding between suitable alternative options for meeting needs. This does not mean choosing the cheapest option; but the one which delivers the outcomes desired for the best value (para 10.27).

Sign off and copies of care plans

- 5.63 The ‘sign off’ of a plan should only occur once the authority has taken ‘all reasonable steps to reach agreement with the person for whom the plan is being prepared’ and ‘any third party involved in the preparation of the plan’ and this ‘agreement should be recorded and a copy placed within the plan’ (para 10.83). If the plan is not agreed then the authority should ‘state the reasons for this and the steps which must be taken to ensure that the plan is signed-off’ (para 10.86).
- 5.64 The Act also requires that a copy of the care and support plan be given to the adult in need/carer (and anyone else they request) (section 25(9) and (10)) and the statutory guidance at para 10.87 makes clear that the copy must be ‘in a format that is accessible to the person for whom the plan is intended’ and copies should also be given to any independent advocate involved. Many care and support plans are computer generated and incomprehensible to all but the initiated. The requirement that the copies be ‘in a format that is accessible’ must require that this practice ends and plain English, jargon free plans are provided to those who require them.

Review of care & support plans

- 5.65 Section 27(1) of the 2014 Act places a general duty on local authorities to keep under review care and support plans and section 27(4) requires that

¹⁰⁶ *R v Gloucestershire County Council ex p Barry* 1 CCLR 40; [1997] 2 All ER 1; and reiterated in *R (KM) v. Cambridgeshire County Council* (2012) [2012] UKSC 23.

if they believe that the circumstances have changed materially, then they must undertake a further needs or carer's assessment and revise the plan accordingly. The guidance creates an expectation that the care and support plans will be reviewed 'no later than every 12 months, although a light-touch review should be considered 6-8 weeks after the plan and personal budget have been signed off' (para 10.42 – and see also para 13.32).

- 5.66 The guidance requires that reviews (like assessments) must be person-centred, accessible and proportionate: must involve the 'person needing care and also the carer where feasible' (para 13.2) and their purpose is to 'identify if the person's needs (or any other circumstances) have changed' (para 13.4). Very welcome is the note in the guidance that the 'review must not be used as a mechanism to arbitrarily reduce the level of a person's personal budget' (para 13.4). Reviews should not be 'overly-complex or bureaucratic' and should cover the specified matters – which 'should be communicated to the person before the review process begins' para 13.12). These include: whether the person's needs/circumstances have changed; what parts of the plan are working/not working/need changing; have the outcomes identified in the plan been achieved and are there any new outcomes they want to meet; is the person's personal budget adequate and is there a need to change the way it is managed/paid; are there material changes in the person's support networks which might impact negatively or positively on the plan; have any changes occurred which could give rise to a risk of abuse or neglect; and is the person, carer, independent advocate satisfied with the plan?
- 5.67 The guidance goes into considerable detail about the different ways that a review may be triggered – i.e. as a result of a planned review (where the date is detailed in the care and support plan); an unplanned review (resulting from a change in needs/circumstances); and a requested review (i.e. by the person with the plan, or any interested party on their behalf) (para 13.13).

6. Services to support carers

- 6.1 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).
- 6.2 The legislative purpose of the assessment, however, is to provide information that enables the social services department to decide what additional care and/or support should be provided:
- a) to the adult in need; and
 - b) to the carer.

Carers services provided under the Care Act

- 6.3 This section considers the legal obligations to provide support for a carer in situations where both the carer and the person 'in need' are adults. The legal obligations that arise where the care is being provided by a young carer or the person 'in need' is under 18 are considered separately at chapters 9 and 10.
- 6.4 As noted above the outcome of a carer's assessment will not infrequently be that the carer's eligible needs will be addressed by providing care and support to the person for whom they care. Thus, if a carer is no longer willing or able to provide help with (for example) bathing, the adult in need's care and support 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 adult (because s/he has obtained employment or simply needs to take a break) then the plan will need to specify how the adult's need for supervision/support at such times will be met in the future.

Replacement/respice/short break support

- 6.5 Historically, support arrangements that replace the care that has been provided by a carer have been referred to as 'respice care' or 'short breaks' support. This type of care is referred to in the statutory guidance to the Care Act as 'replacement care' which is in many respects a better description of what is involved. As noted above (para 5.56), if replacement care of this kind is charged for, then it will be the adult in need, not the carer that is liable for the charge.
- 6.6 The importance of timely respice care/short break services has been

repeatedly highlighted by research, guidance and case law.¹⁰⁷ By way of example, guidance to the 1995 Act¹⁰⁸ 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’.¹⁰⁹

- 6.7 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’.
- 6.8 Not infrequently local authorities experience difficulties in addressing the specific replacement care needs of adults in need and their carers. In 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).¹¹⁰ A further example is provided in a 2011 report¹¹¹ 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 British Sign Language (BSL) skills. To this the Ombudsman commented: ‘There is no evidence that it considered the obvious and sensible expedient 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.’
- 6.9 Replacement care can be facilitated by the provision of a sitting service (including an overnight sitting service); by the adult in need spending time in another setting (such as a care home or community centre); or 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 6.17 below) or they might be provided with a joint holiday. 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 behaviour¹¹²). 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

¹⁰⁷ 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

¹⁰⁸ 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.

¹⁰⁹ D Challis et al, *Care Management and Health Care of Older People* (Canterbury 1995).

¹¹⁰ Complaint no 10 000 207; 10 004 245; & 11 000 195 against Southwark LBC, 22 May 2012 para 94.

¹¹¹ Complaint no 09 004 278 against Leeds City Council, 1st July 2011 (para 153 – 154).

¹¹² Ombudsman’s Report on a complaint against Complaint v Torfean CBC No. 1712/200600588 11 January 2008 at para 132.

should not have the same right to respite support as carers of persons with other impairments.¹¹³

Withdrawing/not providing respite care.

- 6.10 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:¹¹⁴

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.

- 6.11 In relation to waiting lists, the court and Ombudsman have been similarly forceful. The Ombudsman in a complaint report concerning Essex¹¹⁵ has stated:

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

- 6.12 An Ombudsman's complaint against North Yorkshire County Council¹¹⁶ 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.
- 6.13 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

¹¹³ In this regard, see Care Services Improvement Partnership (CSIP) *Creative models of short breaks (respite care) for people with dementia* (2008)

¹¹⁴ *R v South Lanarkshire Council ex p MacGregor* (2000) 4 CCLR 188.

¹¹⁵ Complaint 00/B/00599 3rd September 2001; and see also *R v Islington LBC ex p Rixon* (1996)1 CCLR 119.

¹¹⁶ Complaint 01/C/03521 against North Yorkshire 19th August 2002: [the names used are not the real names].

nervous breakdowns and their marriage of 25 years ended.

- 6.14 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, 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.

Support provided directly to the carer

- 6.15 Although carers are generally supported by ensuring that the care and support package for the adult in need is appropriate and of high quality, the Care Act (as with the previous legislation¹¹⁷) provides for support services to be delivered directly to the carer. Para 11.41 of the statutory guidance gives examples of the type of support that are envisaged for carers:

relaxation classes, training on stress management, gym or leisure centre membership, adult learning, development of new work skills or refreshing existing skills (so they might be able to stay in paid employment alongside caring or take up return to paid work), pursuit of hobbies such as the purchase of a garden shed, or purchase of a laptop so they can stay in touch with family and friends.

- 6.16 The above examples are illustrative: accordingly local authorities will be able to continue with the range of supports provided under the pre-Care Act regime for which examples in the previous guidance included:

trips (such as holidays or on special events); driving lessons; travel

¹¹⁷ Principally under the Carers & Disabled Children Act 2000 section 2.

assistance (including for instance help with taxi fares); training; laundry; gardening; help with housework;¹¹⁸ 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;¹¹⁹ 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 relation to come from another country to care for a woman with MS that rural homecare could not deliver.¹²⁰

Direct payments

- 6.17 Where a carer is eligible for support and it is decided that this support be provided directly to the carer, then the Care Act, section 31 (and the regulations¹²¹) provide that the carer has a right to receive a direct payment instead of being provided 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 direct payment – with which he or she then undertakes to purchase the service assessed as being required.
- 6.18 Guidance on the direct payments scheme is found in chapter 12 of the statutory guidance to the Care Act which considers 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.
- 6.19 It should of course be appreciated that where short break/respite/replacement care is provided (e.g. a sitting service) this will be a service provided to the adult in need and so would be recorded on their care and support plan. If he or she wants a direct payment in lieu of the local authority providing this service, then this can only be done if they meet the direct payment requirements – e.g. are able to manage the payment alone or with assistance – or the authority is able to pay it to a third party (for instance the carer) using its powers under the Care Act 2014, section 32.
- 6.20 Where an adult in need or a carer is assessed as needing a service, then in general there is a duty¹²² 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 s/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

¹¹⁸ 2000: ‘Carers and people with parental responsibility for disabled children’: Practice Guidance 2001.

¹¹⁹ Department of Health ‘Carers and Disabled Children Act Combined Policy Guidance under the 2000 & 2004 Acts’ (2005) at para 65.

¹²⁰ Social Care Institute for Excellence (SCIE) ‘Practice guide 5: Implementing the Carers (Equal Opportunities) Act 2004’ (SCIE 2005) p.30.

¹²¹ *The Care and Support (Direct Payments) Regulations 2014* SI 2871.

¹²² A (very) few individuals are not permitted to have direct payments – most commonly those subject to a drug rehabilitation or alcohol treatment requirement – see *The Care and Support (Direct Payments) Regulations 2014* SI 2871, Schedule 1.

- was the responsibility of the parents, whether or not children have a disability'¹²³ (and see also para 11.8 below);
- to have a policy of refusing direct payments for certain services – such as short (overnight) breaks.¹²⁴
- 6.21 The relevant social security regulations require 'any payment' made under the direct payments legislation to be disregarded for benefits purposes.¹²⁵ This does not, however, apply to carers who are paid using these payments – since the disregard does not apply to 'earnings'.¹²⁶
- 6.22 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 'it is necessary to do so'.¹²⁷ This is a much lower threshold test than under the pre-Care Act regime and authorities will need to amend their policies on this question.
- 6.23 Where a direct payment is being used to pay a carer to provide care, it can have several negative effects. The direct payment would be earnings and therefore counted as income for benefits purposes. This would affect any means-tested benefits such as Income Support and could also potentially disentitle carers to Carer's Allowance depending on the level of earnings per week. Finally, this could also undermine the right of carers 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.¹²⁸ Whether the right to an assessment is lost by such an arrangement will depend on the facts in each case – but if the carer is also providing unpaid care, this element would entitle them to an assessment. In this context the statutory guidance at para 6.17 advises that in addition to considering the unpaid element, the authority should consider if:

the nature of their relationship with the person cared for is such that they ought to be considered as a "carer" within the scope of the Act. The local authority has the power to carry out an assessment in such cases, if it judges that there is reason to do so.

Personal budgets

- 6.24 Local authorities must (it appears¹²⁹) specify in a carer's support plan the amount of their 'personal budget'. A personal budget is essentially the cost that a local authority incurs (or would incur) in order to meet the eligible

¹²³ Public Service Ombudsman (Wales) Complaint No. B2004/0707/S/370 against Swansea City Council 22 February 2007 see in particular paras 78, 133 & 137.

¹²⁴ 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'.

¹²⁵ 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.

¹²⁶ See *Casewell v. Secretary of State for Work and Pensions* [2008] EWCA Civ 524.

¹²⁷ *The Care and Support (Direct Payments) Regulations 2014* SI 2871, regulation 3(2).

¹²⁸ Care Act 2014 section 10(9).

¹²⁹ Section 25 distinguishes between 'adults' and 'carers' but it would appear that the reference in section 25(1)(e) (the duty to include a personal budget) is intended to include both 'adults' and 'carers'.

needs of the carer (or the adult for whom they care). The amount of a personal budget may not be of great interest to the carer/adult in need, unless it is actually paid in the form of a direct payment. However, regardless of whether it is simply a statement of the costs borne by the local authority or the amount of a direct payment – it must be sufficient to meet the carer’s eligible needs (section 26). Local authorities will also detail in the budget the amount (if any) the individual will have to pay in charges: para 11.10 of the statutory guidance states:

The personal budget must always be an amount sufficient to meet the person’s care and support needs, and must include the cost to the local authority of meeting the person’s needs which the local authority is under a duty to meet, or has exercised its power to do so. This overall cost must then be broken down into the amount the person must pay, following the financial assessment, and the remainder of the budget that the authority will pay.

- 6.25 The guidance at para 11.34 suggests the pooling of budgets, for example, where an adult and a carer are living in the same household. The guidance considers, however, the possible complexities that may arise when it is unclear as to whether a particular service is for a carer or for the ‘adult’ – para 11.38 advising that local authorities:

should consider how to align personal budgets where they are meeting the needs of both the carer and the adult needing care concurrently. Where an adult has eligible needs for care and support, and has a personal budget and care and support plan in their own right, and the carer’s needs can be met, in part or in full, by the provision of care and support to that person needing care, then this kind of provision should be incorporated into the plan and personal budget of the person with care needs, as well as being detailed in a care and support plan for the carer.

- 6.26 A number of local authorities pay carers a generalised ‘lump sum’ personal budget – which gives the carer freedom to decide how this should be paid (e.g. on a recreational, social, educational activity etc.). Despite concerns that the allocation process may be ‘haphazard’¹³⁰ there appears to be no reason why these payments should not continue under the Care Act regime – and of course such arrangements have the merit of relative administrative simplicity. Local authorities will however need to ensure that the payments are sufficient to meet carers’ eligible needs and that there are not arbitrary low ceilings on the amount of support carers can receive.

¹³⁰ See for example W Mitchell ‘How local authorities allocate resources to carers through carer personal budgets’ Research Findings, (2014) NIHR School For Social Care Research, London.

7. The NHS's responsibilities

General carer obligations

- 7.1 No English legislation imposes 'carer' explicit obligations on the NHS, in contrast to the situation in Scotland¹³¹ and Wales.¹³² A number of initiatives to address this problem have been opposed by successive governments¹³³ despite the extensive research concerning the caring related health problems that carers experience.
- 7.2 In addition to the ill-health carers experience (see para 5.32 above), NHS data suggests that 66% of carers feel that healthcare staff don't help to signpost them to relevant information and although 70% of carers come into contact with health professionals, health professionals only identify one in ten of them as carers.¹³⁴ 2014 research by Carers UK found that only a third of carers reported a positive experience of NHS services over the previous year, while 16% had negative experiences.¹³⁵ In April 2014 NHS England published a 'commitment to carers'¹³⁶ in which it accepted that the NHS needed to become 'dramatically better at involving carers' and in December 2014 this was followed by its 'Commissioning for Carers' guide.¹³⁷
- 7.3 The NHS Constitution (2013)¹³⁸ commits the NHS to work in partnership with patients and carers and to ensure that 'care is coordinated around the needs, convenience and choices of patients, their carers and families'. It lists seven key principles to 'guide the NHS in all it does', of which Principle Four is:
- It recognises the need for patients, along with their families and carers, to be involved in discussions about their care, where it is appropriate to do so.*
- 7.4 The performance of NHS bodies are assessed in a number of ways – including by reference to the 'The NHS Outcomes Framework'¹³⁹ which contains an Indicator measure (2.4) that concerns the 'Health-related quality of life for carers'.
- 7.5 These general 'macro' policy commitments appear to have done little in practical terms to improve the micro experiences of carers – i.e. when confronted with a hospital discharge and the shortage of community support

¹³¹ The Community Care and Health (Scotland) Act 2002

¹³² The Carers Strategies (Wales) Measure 2010 obliges Local Health Boards considered at para 4.26 of the 5th edition of this Guide.

¹³³ For a brief review of the attempt to fill this lacuna via the Carers (Equal Opportunities) Act 2004 see para 7.8 of the 5th edition of this Guide.

¹³⁴ NHS England *Commitment to Carers* (2014) p.7.

¹³⁵ Carers UK, *Quality of care and carers*, (2014)

¹³⁶ NHS England *Commitment to Carers* (2014)

¹³⁷ NHS England *Commissioning for Carers* (2014)

¹³⁸ Department of Health *'The Handbook to the NHS Constitution for England'* (2013) section 3a – to which every NHS body in England must have regard - Health Act 2009 section 2.

¹³⁹ Department of Health *'The NHS Outcomes Framework 2014/15'*.

services¹⁴⁰ (to address the 50% decline in hospital beds that has occurred in the last 30 years¹⁴¹).

- 7.6 References in aspirational documents such as the ‘commitment to carers’ (above) can convey an impression of seamless joint working – which is in stark contrast to the experiences of some carers: ‘experiences of bullying tactics’ and of hospitals ‘not being interested in [the carers’] wellbeing’; hospitals pressing for hospital ‘discharge, even though this was not supported by in-house social services staff’.¹⁴² In relation to these two quotes the hospital in question was reported as threatening to take legal action to evict ‘mainly elderly patients whose relatives refuse to take them home’¹⁴³ – notwithstanding that at law ‘relatives’ have no legal duties in this respect.
- 7.7 There are however many examples of good practice within the NHS system and a 2015 NHS England ‘toolkit’ referred NHS trusts to various initiatives for patients and carers – including introducing a ‘carers’ passport’ to encourage carers to come into the acute setting ‘to provide help and support for the person with dementia, and facilitate free parking and open access to the ward’.¹⁴⁴

The NHS duty to co-operate

- 7.8 2005 research evidence produced by the Patients Association¹⁴⁵ 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. Over half of carers have experienced difficulties in the way NHS and social care services work together.¹⁴⁶
- 7.9 There are a number of statutory duties on local authorities and the NHS to work together constructively, most importantly under 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 suffers 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.
- 7.10 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

¹⁴⁰ See for example, Kings Fund ‘Community services How they can transform care’ (2014)

¹⁴¹ NHS England ‘Bed Availability and Occupancy Data – Overnight’ (2015) based on ‘KH03’ returns from all NHS organisations that operate beds.

¹⁴² Healthwatch Dorset A statement from Healthwatch Dorset in response to reports that the Royal Bournemouth Hospital has threatened to evict elderly patients (21/11/2014)

¹⁴³ The Independent ‘Royal Bournemouth Hospital threatens to evict elderly patients’ Saturday 04 April 2015

¹⁴⁴ NHS England A toolkit to support NHS commissioners to reduce poor experience of in-patient Care (2015) at page 24

¹⁴⁵ Who Will Look After Mum? June 2005

¹⁴⁶ Carers UK, Quality of care and carers (2014)

of maladministration. In her opinion, having accepted that a need existed, social services should have 'grasped the nettle' and secured the provision, before entering into protracted negotiations with the NHS on liability for the care costs.¹⁴⁷

- 7.11 Joint working difficulties can arise due to NHS bodies failing to work with each other and accordingly the NHS Act 2006, section 72, requires NHS bodies to co-operate with each other in exercising their functions.
- 7.12 The Care Act 2014, section 6 adds a further joint working duty on local authorities and NHS bodies (and other 'relevant partners'¹⁴⁸) to co-operate with each other. This general duty is augmented by a power in section 7 that enables local authorities to request co-operation in specific cases – and that partner bodies must comply with such requests or give written reasons as to why it will not (and this must be either because it would be 'incompatible' with its duties' or 'would have an adverse effect on the exercise of its functions'). The statutory guidance to the Care Act suggests (para 2.35) that the section 6 and 7 powers might be invoked by authorities in relation to the 'provision of preventative services and the identification of carers'.
- 7.13 In almost identical terms to the Care Act section 7 duty, the Children Act 1989 section 27 enables local authorities to request co-operation in specific cases. In addition, the Children Act 2004 section 10 requires each local authority to make arrangements to promote cooperation with the NHS and other relevant partners.¹⁴⁹

Hospital discharge

- 7.14 All patients are owed a duty of care by 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.
- 7.15 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 guidance¹⁵⁰ 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

¹⁴⁷ 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).

¹⁴⁸ For example, housing authorities, the NHS, police, probation etc.

¹⁴⁹ For example, housing authorities, the NHS, police, probation etc.

¹⁵⁰ *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care* (2010) Department of Health at p27.

*to achieve what they considered would be best for their relatives.*¹⁵¹

- 7.16 '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.
- 7.17 Although patients have, in general,¹⁵² 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.
- 7.18 The relationship between the NHS and social services in the discharge process is shaped by central government guidance, and additionally by statute – the Care Act 2014, section 74 and Schedule 3 and the associated regulations.¹⁵³
- 7.19 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)*¹⁵⁴ which supersedes (rather than repeals¹⁵⁵) the more extensive 2003 guidance *Discharge from hospital: pathway, process and practice*.¹⁵⁶

Patient and carer involvement

- 7.20 The 2003 pathway's guidance states that 'the engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge' (para 1.4). It further stresses the importance of patients and their carers being 'kept fully informed by regular reviews and updates of the care plan'.¹⁵⁷ 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'.
- 7.21 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 situations.¹⁵⁸ Working with carers is a responsibility of

¹⁵¹ Hubbard et al (2008) *Reimbursement in practice: The last piece of the jigsaw?* University of Stirling, University of Leeds, King's College London.

¹⁵² 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,

¹⁵³ *The Care and Support (Discharge of Hospital Patients) Regulations 2014* SI 2823.

¹⁵⁴ Department of Health *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care (2010)*.

¹⁵⁵ The 2010 *Ready to go?* guidance cites the 2003 *Pathways* guidance on a number of occasions.

¹⁵⁶ Department of Health *Discharge from hospital: pathway, process and practice (2003)*.

¹⁵⁷ Para 1.2 and at para 4.5.1 provides a detailed 'carer's checklist' of relevant factors to be considered.

¹⁵⁸ Carers UK, *State of Caring Survey 2011*: 42% of those caring for someone discharged from hospital, felt that the person they care for was not ready to come out or that they did not have the right support to be at home. 54% of those caring someone discharged from hospital had either not been consulted with about their discharge or only consulted at the last minute.

discharge coordinators – and it should not be seen merely as a social services function.

7.22 The 2003 guidance (page 38) refers to ‘circumstances where patients refuse permission to allow the carer to be involved in decisions about their future care’ and advises that in such cases ‘carers should be informed of this and their right to an assessment reinforced’. With the advent of the new Care Act duties to carers, this advice must be interpreted with considerably greater force. As noted above (para 3.5) any assessment of an adult in need must involve their carer (section 9(5)) as must the preparation of any care and support plan for that person (section 25(3)).

7.23 Para 4.3, of the 2003 guidance stresses the importance of carers being 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’. It then adds:

The needs 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.

7.24 The 2010 guidance (although in need of updating¹⁵⁹) contains a number of important points relating to the involvement of carers in the hospital discharge process – which can be summarised as follows:

- Early identification of carers at the point of admission: ‘carers should be involved in decision-making from the beginning’ (page 29);
- Involvement of carers throughout the journey: patients and carers are involved at all stages of discharge planning (page 7 – key principles);
- Involvement that is meaningful – ‘action not just words’ (page 31); patients, carers and everyone involved in the discharge plan are kept informed of any changes (page 24). In the light of the Care Act obligations (para 3.7 above) this process must also place particular emphasis on the carer’s employment and their other

¹⁵⁹ The need arises in part because the guidance refers to repealed provisions such as the Community Care (Delayed Discharges etc.) Act 2003 and the choice of accommodation directions – but more importantly to reflect the new rights of carers and the need for discharge planning to adopt a ‘whole family approach’ (see para 10.23).

responsibilities including childcare;

- Takes account of the carer's health and wellbeing – the advice at page 19 to 'offer the carer an assessment to identify any services they may need to support them in their caring role' must now be read in the wider context of: (1) the Care Act obligations (para 3.7 above) to promote well-being; and (2) the obligation not to assume that carers are willing or able to provide care – which the guidance echoes at page 12 'don't assume that a person's carer will necessarily be able to, or want to, continue in a caring role. Patients and their carers may have different needs and aspirations'.
- Provides advice on the skills they need such as moving and handling, medication advice, advice on equipment or clinical issues such as where a catheter might be in place etc., 'not to assume all carers are expert in the techniques that may be required to nurse the adult in need' (page 27) and the requirement that the patient and the carer have 'written information regarding care and treatment, medication, dressings and equipment,...prepared in advance, ready for transfer with the patient' (page 25).
- Information of wider sources of support – the need for a full range of information is stressed throughout the 2010 guidance.
- Carers' assessments (including young carers' assessments) adopt (what is now referred to as) a 'whole family approach' (see para 10.23).

'Discharge to Assess' models

- 7.25 Increasingly hospitals are adopting a model of discharge (particularly for frail older people) referred to as a 'Discharge to Assess' model to distinguish it from the traditional 'Assess to Discharge' model. Rather than a discharge waiting for assessments from the key health and social care rehabilitation staff (including occupational therapists and physiotherapists), a community team including such experts, assesses the patient's ongoing care and therapy needs at home. There is evidence to support this approach both in terms of patient/carer satisfaction as well as the efficient use of health care resources. Whatever model is adopted, it must comply with the hospital discharge guidance, the Care Act duties and the requirements of the common law 'duty of care'. This means (among other things) that before the process is instigated a carer's risk assessment must be undertaken to ensure that they are not placed at risk (in terms of their health, employment, family life, etc.) and that their willingness to care is recorded and honoured.

Reablement and community equipment

- 7.26 Certain support services following discharge must be provided free of charge. These include 'intermediate care' (often referred to as 'reablement') which can be provided for up to six weeks as well as community equipment (i.e. aids and minor adaptations) – even if not following discharge, but merely provided to meet or prevent/delay needs developing (a minor adaptation is

one costing £1,000 or less).¹⁶⁰

Information /communication

- 7.27 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. The Ombudsman has stressed that where the obligation to inform is shared jointly with social services, this does not excuse a failure by the hospital to provide the information (i.e. it cannot assume that social services will discharge its duty)¹⁶¹. The Ombudsman has also criticised as inadequate the provision of general brochures to patients and situations where staff provided patients and their carers with only limited advice on their possible options.¹⁶²
- 7.28 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).

Delayed discharge penalties for local authorities

- 7.29 The Care Act 2014, section 74 and Schedule 3 and the associated regulations¹⁶³ contain provisions designed to encourage social services to speed up the discharge of patients who no longer require care in an acute hospital¹⁶⁴ although, as the statutory guidance to the Care Act notes at para 15.43, 'the majority of delayed discharge days are attributable to the NHS'. Schedule 3 enables a hospital to serve on the relevant social services department an 'assessment' notice advising that a named patient is likely to be ready for discharge on a specified date. Within 2 days of receiving this notice the social services department must undertake an assessment of the patient's needs and an assessment of any person caring for the patient (reg 8).
- 7.30 Before issuing the assessment notice, the NHS body must 'consult the patient, and where it is feasible to do so, any carer that the patient has'¹⁶⁵ and the notice must state that this has been done and whether the patient/ the patient's carer has objected to the giving of the assessment notice'.¹⁶⁶ As noted below, a refusal by the patient (or the carer, if the discharge is dependent upon their involvement) has the effect of absolving the local authority from the liability to pay the discharge penalty.
- 7.31 The NHS may issue a 'discharge' notice giving at least one day's notice of

¹⁶⁰ See *The Care and Support (Charging and Assessment of Resources) Regulations 2014* SI 2672 regulation 3 and the *statutory guidance* para 8.14.

¹⁶¹ Fifth Report for session 1995-96, *Investigations of Complaints about Long-Term NHS Care*, HMSO, complaint E.685/94-95

¹⁶² The above cited NHS Ombudsman's Report, complaint E.672/94-95.

¹⁶³ *The Care and Support (Discharge of Hospital Patients) Regulations 2014* SI 2823.

¹⁶⁴ Maternity care, mental health care, palliative care, intermediate care and care provided for recuperation or rehabilitation are excluded from the definition of acute care.

¹⁶⁵ Care Act 2014, para 1(4) Schedule 3.

¹⁶⁶ *The Care and Support Discharge of Hospital Patients) Regulations 2014* SI 2823 Reg 3(f)(iii).

the required discharge, and if after this the patient cannot be discharge for the 'reason alone'¹⁶⁷ that the local authority has not carried out the relevant assessments or put in place arrangements 'for meeting some or all' of the identified eligible needs, then it is liable to make a payment to the NHS (as of 2015 at £155 or £130 per day depending on whether it is a London Borough).

- 7.32 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.

NHS Continuing Healthcare

- 7.33 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.¹⁶⁸
- 7.34 In the leading case on this question, *R v. North and East Devon health authority ex p Coughlan*¹⁶⁹, the Court of Appeal held that in general social services authorities had no responsibility for people who were eligible for NHS Continuing Healthcare support. Local authorities remain responsible for undertaking assessments of those caring for people who are eligible for NHS funding and providing support to the carers where required. However if the support required involves the provision of 'respite/short break/replacement care' to the adult in need – then this will be the responsibility of the NHS. Not infrequently the NHS is resistant to providing such support or inflexible in the way it responds. In such cases it may be necessary for the local authority to use its power under sections 6 and 7 of the 2014 Act to ensure that the necessary care is provided (see para 7.12 above).

¹⁶⁷ Schedule 3 para 4(2).

¹⁶⁸ For a detailed review of this area of law see L Clements (2015) *Community Care and the Law* 6th edition Legal Action Group, London chapter 14.

¹⁶⁹ *R v. North and East Devon health authority ex p Coughlan* [2000] 2 WLR 62.

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/help

The entitlement rules for Carer's Allowance (and process for claiming it) can be accessed at the 'Directgov' information site at:

www.gov.uk/carers-allowance

Paying for services provided by social services departments

8.2 Social services departments are permitted to charge adults in need and carers for the support that is provided under the Care Act 2014 (unless it is for certain forms of reablement/intermediate care (see para 7.26 above). The statutory guidance (at para 8.2) provides a single set of principles that all authorities must follow in relation to their charging policies, namely:

- ensure that people are not charged more than it is reasonably practicable for them to pay;
- be comprehensive, to reduce variation in the way people are assessed and charged;
- be clear and transparent, so people know what they will be charged;
- promote wellbeing, social inclusion, and support the vision of personalisation, independence, choice and control;
- support carers to look after their own health and wellbeing and to care effectively and safely;
- be person-focused, reflecting the variety of care and caring journeys and the variety of options available to meet their needs;
- apply the charging rules equally so those with similar needs or services are treated the same and minimise anomalies between different care settings;
- encourage and enable those who wish to stay in or take up employment, education or training or plan for the future costs of meeting their needs to do so; and
- be sustainable for local authorities in the long-term.

8.3 One problem with the approach of applying 'the charging rules equally so those with similar needs or services are treated the same' is that local authorities may start charging carers for services. The guidance anticipates this problem – but cautions authorities against this stating (para 8.50):

Local authorities are not required to charge a carer for support. ... A local authority should consider how it wishes to express the way

it values carers within its local community as partners in care, and recognise the significant contribution carers make. ... Local authorities should consider carefully the likely impact of any charges on carers, particularly in terms of their willingness and ability to continue their caring responsibilities.

- 8.4 The charging rules only permit the person receiving the care and support to be charged and so only their financial circumstances that can be taken into account. This means that even if the carer and the adult in need are married, their financial circumstances should not be aggregated.

Treatment of property when an adult in need enters a care home

- 8.5 Annex B to the statutory guidance to the Care Act (para 34) 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 unless one of the following disregards apply:
- a) where the person is receiving care in a setting that is not a care home
 - b) if the person's stay in a care home is temporary and they either:
 - i intend to return to that property and that property is still available to them
 - ii are taking reasonable steps to dispose of the property in order to acquire another more suitable property to return to
 - c) where the person no longer occupies the property but it is occupied in part or whole as their main or only home by any of the people listed below, the mandatory disregard only applies where the property has been continuously occupied since before the person went into a care home (for discretionary disregards see below):
 - i the person's partner, former partner or civil partner, except where they are estranged
 - ii a lone parent who is the person's estranged or divorced partner;
 - iii a relative as defined in paragraph 35 of the person or member of the person's family who is either:
 1. aged 60 or over
 2. is a child of the resident aged under 18
 3. is incapacitated
- 8.6 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 (para 47(d) Annex B statutory guidance);
- 8.7 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: para 42 Annex B statutory guidance suggests that authorities:

will need to balance this discretion with ensuring a person's assets are not maintained at public expense. An example where it may be appropriate to apply the disregard is where it is the sole residence of someone who has given up their own home in order to care for the person who is now in a care home or is perhaps the elderly companion of the person.

- 8.8 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 stepchild 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.

9. The rights of disabled children – an overview

- 9.1 Chapter 4 provides an overview of the rights of adults 'in need'. These derive from the Care Act 2014 as do the rights of people who provide care for them.
- 9.2 The Act that plays a primary role in determining the social care rights of disabled children and their carers is the Children Act (CA) 1989: it is an Act that is also pivotal to determining the social care rights of young carers and the parents of disabled children. This chapter provides therefore a brief overview of the rights of disabled children – and is succeeded by chapters that consider the rights of young carers and parent carers.
- 9.3 The definition of a disabled child is contained in CA 1989 section 17(11) and is widely drawn – namely a child who is:
- blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity ... ; and 'development' means physical, intellectual, emotional, social or behavioural development; and 'health' means physical or mental health.*
- 9.4 It follows that children with high functioning autism, Asperger Syndrome, hyperactive and attention deficit disorders fall within the definition – as well as those with more 'recognised' disabilities such as learning disabilities, physical impairments, mental illnesses etc.

The assessment of disabled children's needs

- 9.5 As with the assessment of adults in need, there is a three stage process by which the entitlements of disabled children are determined: (1) a data gathering process to identify the child's needs; (2) an eligibility process – which determines which of these needs are eligible; and (3) the preparation of a care and support plan that details how the eligible needs will be met in practice.
- 9.6 The most significant difference between assessments of adults under the Care Act 2014 and assessments of disabled children under the Children Act 1989 Act is that there is no single set of statutory eligibility criteria that applies to disabled children. Although it is necessary for children's services to have criteria by which they determine entitlement, all too often these tend to be 'poorly publicised and formulated with little or no consultation ... [and] inappropriate for many families with disabled children or young carers'.¹⁷⁰

¹⁷⁰ L Clements and P Thompson *Community Care and the Law* 5th edition (2011 Legal Action) para 24.36.

9.7

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 – for which the key guidance is *Working Together* (2015)¹⁷¹ (see para 10.18 below).

Stage 1

The social worker will get full details of Rupee's social care needs. This will include discovering 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 wishes to return to work as a teacher (but has been unable to do so due to Rupee's disability-related care needs) and that Rupee's brother is also providing her with significant amounts of care. The responsibility of the local authority to promote the mother's wish to work is considered at para 11.8 below – as is the question of their responsibilities towards 'young carers' (see chapter 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 in the short term the family needs 'breaks' from their caring role – i.e. a need for short break or 'respite care' – see para 6.5. This might mean that Rupee would stay elsewhere for a period (i.e. with temporary foster parents) or that someone comes to her home and sits with her, whilst other family members have a break from their caring roles. In the medium term it may be decided that care and support arrangements should be arranged to enable Rupee's mother to return to work (and pending this she be helped attend a training/education programme to update her teaching skills). In assessing whether this support should be made available, the social services department would have regard to the consequences (among other things) if no help is provided.

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. In this case it would spell out when, where and how often respite care support will be provided, together with a short/medium term plan that will enable Rupee's mother to return to work, together with details of other general assistance that will be made available. The services that Rupee and her family require would be provided under the CA 1989 section 17 and/ or the Chronically Sick and Disabled Persons Act 1970, section 2. These cover a wide range of support arrangements (for

¹⁷¹ HM Government *Working together to safeguard children* (2015) issued under section 7 of the Local Authority Social Services Act 1970, which requires authorities 'to act under' such guidance.

example, respite/short-break care, community based support such as after school clubs as well as adaptations/equipment etc. – and are considered further at 10.42 – 10.44 below.)

Disabled children 'in transition'

- 9.8 Local authorities have specific care planning obligations to disabled young people who are approaching the time when their care needs will become the responsibility of the adult social services department. These responsibilities mirror the obligations owed to those caring for such disabled children – as well as to young carers who are approaching this 'transition'. The rights of young carers and parent carers in this process are detailed separately below (see paras 10.48 and 11.22). Consideration of the rights of disabled young people in transition is outside the scope of this text – but a number of guides are available that address this question.¹⁷²

¹⁷² See for example, S Broach et al *Disabled Children: A Legal Handbook* 2nd edition (Legal Action Group 2015); SCIE *The Care Act: Transition from childhood to adulthood* (SCIE 2014); and C Parker *Transition to Adulthood* (Cerebra 2013).

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.¹⁷³ It appears that 66% of young carers care for their parents, 31% care for their siblings,¹⁷⁴ 3% care for their grandparents and 1% care for wider family or community members. In addition, 10% of young carers care for more than one person.¹⁷⁵
- 10.2 2015 guidance published by the Department of Health (and others)¹⁷⁶ cited the following statistics:
- One in 12 young carers, cares for more than 15 hours per week and about one in 20 misses school because of their caring responsibilities.
 - The average annual income for families with a young carer is £5,000 less than families who do not have a young carer.
 - There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
 - Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine Bs and nine Cs.
 - Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.
- 10.3 The Equality and Human Rights Commission’s (EHRC) in its 2010 Equality Review,¹⁷⁷ 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, Black Caribbean and Pakistani).
- 10.4 The EHRC’s emphasis on considering the position of young carers from a human rights perspective is important. As Lord Kerr’s judgment has observed:¹⁷⁸

It is a universal theme of the various international and domestic instruments ... that, in reaching decisions that will affect a child, a

¹⁷³ D Howard (2010) *Cameron warns on child carer cuts* 16th November 2010 at www.bbc.co.uk/news/education-11757907

¹⁷⁴ A 2013 US study looking at the siblings of disabled children found that they were almost three times more likely to have significant levels of problems in interpersonal relationships, their psychological well-being, school performance, or use of leisure compared to other siblings – see Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T., ‘Assessing functional impairment in siblings living with children with disability’ in *Pediatrics* Vol. 132 No. 2 August 1, 2013.

¹⁷⁵ C Dearden, and S Becker ‘*Young Carers in the UK: The 2004 Report*’ (Carers UK and The Children’s Society (2004).

¹⁷⁶ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015) and see also The Children’s Society *Hidden from view* (2013).

¹⁷⁷ Equality and Human Rights Commission (2010) *How fair is Britain?* Executive Summary p33.

¹⁷⁸ *ZH v Secretary of State for the Home Department* [2011] UKSC 4.

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.

- 10.5 ‘Young carers’ were not mentioned in any legislation prior to the enactment of the Care Act 2014 and the Children and Families Act 2014. As a consequence some authorities had been reluctant to undertake separate ‘carer’s’ assessments of people under 18 who were acting as carers for family or friends. This failure was generally unlawful since there was a duty on such authorities to assess all carers (regardless of their age) who were providing substantial amounts of care on an unpaid basis: a duty referred to on a number of occasions by the courts and Ombudsman.¹⁷⁹ The 2014 Acts are now explicit in identifying ‘young carers’ as rights holders: people for whom local authorities have a duty to assess and – where their needs call for support – a duty to provide this under either the Care Act 2014 (if provided to an adult) or the Children Act – see below.

Definition

- 10.6 The Children Act 1989¹⁸⁰ defines a young carer as ‘a person under 18 who provides or intends to provide care for another person’ but it excludes those who provide this care either as part of their paid employment or as part of formal ‘voluntary work’.¹⁸¹ The same definition is provided by the Care Act 2014.¹⁸² ‘Care’ in this context includes emotional as well as ‘practical support’.¹⁸³

Strategic obligations

- 10.7 Local authorities are now under a strategic duty to identify the extent to which there are young carers within their area who have needs for support.¹⁸⁴ This strategic planning obligation is reinforced by the statutory guidance to the Care Act which highlights the importance of authorities being proactive in identifying young carers (particularly those not receiving services) who are in transition into adulthood and whose caring role is likely to continue. Authorities are required to consider establishing ‘mechanisms in partnership with local educational institutions, health services and other agencies’ (para 16.19) and the guidance gives as examples of those who might be targeted, including (para 16.18):
- young people (for example, with autism) whose needs have been largely met by their educational institution, but who once they

¹⁷⁹ Complaint No 07B 04696 and 07B 10996 against LB Croydon 16th September 2009, and see also Cerebra Legal Entitlements research project *Digest of Cases 2014 – Kumar’s Story* (page 20) and *Peter’s Story* (page 24).

¹⁸⁰ Section 17ZA(3) inserted by Children and Families Act 2014, section 96.

¹⁸¹ Children Act 1989 section 17ZB(3).

¹⁸² Care Act 2014, section 63(6).

¹⁸³ Children Act 1989 section 17ZB (5) and Care Act 2014 s63(9).

¹⁸⁴ Children Act 1989 section 17ZA (12).

- leave, will require their needs to be met in some other way;
- young carers whose parents have needs below the local authority's eligibility threshold but may nevertheless require advice or support to fulfil their potential (for example, a child with deaf parents who is undertaking communication support);
 - young people and young carers receiving Children and Adolescent Mental Health Services (CAMHS) may also require care and support as adults even if they did not receive children's services from the local authority.

Duty to co-operate

- 10.8 As noted above (see para 7.12) the duty under the Care Act 2014, section 6 on local authorities to co-operate with their 'relevant partners' (such as housing authorities, the NHS, police, probation etc.) is augmented by a power in section 7 that enables them to request the co-operation in specific cases: a power that includes requests relating to the support needs of young carers. As also noted, the section 7 power mirrors and reinforces the broader power available to authorities under the Children Act 1989 Act, section 27.
- 10.9 In relation to the needs of carers, co-operation also needs to be intra-authority – and in particular between children's services and adult services. 2015 guidance¹⁸⁵ refers to a 'Memorandum of Understanding' prepared to aid joint working between children and adult social services.¹⁸⁶
- 10.10 The 2015 guidance¹⁸⁷ also provides an overview of the strategic approach that local authorities should take to ensure that carers are identified in all contacts that adult and children's services have with the public and that the full spectrum of carers' rights are addressed in this process. The guidance indicates that this should include the two departments having a formal plan and protocol to ensure their activities are properly coordinated.

The specific duty to assess young carers

- 10.11 Local authorities must undertake assessments as to whether a young carer within their area has support needs (and if so, what those needs are) if—
- a) it appears to the authority that the young carer may have needs for support, or
 - b) the authority receives a request from the young carer or a parent of the young carer to assess the young carer's needs for support.¹⁸⁸
- 10.12 The duty to assess is therefore a proactive obligation: one that is triggered by the 'appearance of need' (i.e. there is no requirement that a request is made). The duty arises irrespective of whether the assessment process was initiated under the Care Act or Children Act. Such an assessment is referred

¹⁸⁵ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015) p.2.

¹⁸⁶ <http://adcs.org.uk/early-help/article/no-wrong-doors-working-together-to-support-young-carers-and-their-families>

¹⁸⁷ Department of Health (and others) *The Care Act and Whole-Family Approaches* (2015) pp.3-6.

¹⁸⁸ Children Act 1989, s17ZA(1).

to as a ‘young carer’s needs assessment’.¹⁸⁹

- 10.13 When undertaking an assessment the authority is required to consider whether ‘it is appropriate for the young carer to provide, or continue to provide, care for the person in question’.¹⁹⁰ The authority must involve the young carer, his or her parents¹⁹¹ and any other person any of them wish to be involved¹⁹² and must have regard to:¹⁹³
- a) the extent to which the young carer is participating in or wishes to participate in education, training or recreation, and
 - b) the extent to which the young carer works or wishes to work.
- 10.14 Regulations¹⁹⁴ provide the detail of the local authority ‘young carer’ assessment obligations. These require that authorities undertake such assessments in a manner ‘which is appropriate and proportionate to the needs and circumstances of the young carer’ and that in doing so they have particular regard to (regulation 2):
- a) the young carer’s age, understanding and family circumstances;
 - b) the wishes, feelings and preferences of the young carer;
 - c) any differences of opinion between the young carer, the young carer’s parents and the person cared for, with respect to the care which the young carer provides (or intends to provide); and
 - d) the outcomes the young carer seeks from the assessment.
- 10.15 As with assessments under the Care Act 2014, authorities are required to provide relevant parties¹⁹⁵ with information ‘about the manner and form of the assessment’ to enable the effective participation of those involved. The assessor must have sufficient knowledge and skill (having regard amongst other things to the young carer’s age, sex and understanding), and be appropriately trained – and where necessary the authority is required to consult third parties with ‘expertise and knowledge in relation to the young carer’ and consider any other relevant assessments that have been carried out (regulation 3).
- 10.16 Regulation 4 details what must be determined by the assessment – including:
- a) the amount, nature and type of care which the young carer provides/ intends to provide;
 - b) the extent to which this care is (or will be) relied upon by the family, including the wider family, to maintain the well-being of the person cared for;
 - c) whether the care which the young carer provides (or intends to provide) impacts on the young carer’s well-being, education and

¹⁸⁹ Children Act 1989, s17ZA(2).

¹⁹⁰ Children Act 1989 17ZA(7).

¹⁹¹ 17ZB(2) explains that for this purpose that a ‘parent’ includes those that do and do not have parental responsibility for the child (see footnote 244 below).

¹⁹² Children Act 1989 17ZA(9).

¹⁹³ Children Act 1989 17ZA(8).

¹⁹⁴ The Young Carers’ (Needs Assessments) (England) Regulations 2015 SI 527 made pursuant to the Children Act 1989 17ZB(8) and accessible at www.legislation.gov.uk/ukSI/2015/527/contents/made.

¹⁹⁵ Regulation 2(4) specifies that these are (a) the young carer; (b) the person cared for; (c) the young carer’s parents; and (d) any other person whom the young carer or a parent of the young carer requests should participate in the assessment.

development;

- d) whether any of the tasks which the young carer is performing (or intends to perform) when providing care are excessive or inappropriate for the young carer to perform having regard to all the circumstances, and in particular the carer's age, sex, wishes and feelings;
- e) whether any of the young carer's needs for support could be prevented by providing services to—
 - i) the person cared for, or
 - ii) another member of the young carer's family;
- f) what the young carer's needs for support would be likely to be if the carer were relieved of part or all of the tasks the young carer performs (or intends to perform) when providing care;
- g) whether any other assessment of the needs for support of the young carer or the person cared for has been carried out;
- h) whether the young carer is a child in need;
- i) any actions to be taken as a result of the assessment; and
- j) the arrangements for a future review.

10.17 In relation to (d) above, the statutory guidance para 6.71¹⁹⁶ advises that when a 'local authority is determining whether the tasks a child carries out are inappropriate, it should also take into account the child's own view wherever appropriate'

The general assessment obligation under the Children Act 1989

- 10.18 The enactment of the Children and Families Act 2014 and the publication of the specific regulations¹⁹⁷ concerning the assessment of young carers have created an additional layer of assessment obligations on local authorities: specific duties that remain underpinned by the general Children Act 1989, section 17 assessment obligations on such authorities. These assessment duties are the subject of statutory guidance (sometimes referred to as 'binding' guidance) – namely the *Working Together (2015)*¹⁹⁸ guidance.
- 10.19 The guidance indicates that not all assessments need be complex or multi-disciplinary in nature – for example, assessments concerning a relatively straight forward need where quick action is required (referred to as 'early help assessments') but even with these they should always 'be undertaken with the agreement of the child and their parents or carers' (para 10).
- 10.20 General assessments under the Children Act 1989 (referred to below as CA assessments) are triggered by the child being deemed to be 'in need'. Section 17(10) defines a child in need' if:
- a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local

¹⁹⁶ Department of Health (et al.) *The Care Act and Whole-Family Approaches* (2015) p. 34.

¹⁹⁷ *The Young Carers' (Needs Assessments) (England) Regulations 2015* SI 527 (pursuant to the Children Act 1989 17ZB(8)).

¹⁹⁸ HM Government *Working together to safeguard children* (2015) issued under section 7 of the Local Authority Social Services Act 1970, which requires authorities 'to act under' such guidance.

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.

10.21 In this context, previous guidance¹⁹⁹ has 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.*²⁰⁰

10.22 The threshold for triggering a general CA assessment will be higher than that for a young carer's assessment under section 17ZA (see para 10.11 above) – since this only requires that the local authority is aware of a 'young carer' who 'may have needs for support'. Where a general CA assessment involves a young carer – it will of course have to discharge all the young carer specific assessment obligations discussed above.²⁰¹ CA assessments must be undertaken by a social worker.²⁰²

Whole family approach

10.23 The Care Act 2014, section 12(5) empowers authorities to combine a needs assessment of an adult in need or a carer, with a young carer's assessment as well as any subsequent care and support plan (section 25(11)): in both cases the decision to combine is contingent on the agreement of both parties. In similar terms the Children Act 1989, section 17ZB(7) enables Children Act assessments of young carers to be combined.

10.24 The Young Carers' Assessments Regulations²⁰³ require authorities to consider whether to combine assessments in such cases – and the consultation document accompanying the draft Regulations explained that the intention was to promote a 'whole family approach' to assessments:

an assessment that takes into account and evaluates how the needs of the person being cared for impact on the needs of the child who is identified as a possible young carer, or on any other child or on other members of the household. This approach also allows the local authority to combine a young carer's needs assessment with any other assessment in relation to the young carer, the person cared for or another member of the young carer's family.

10.25 The statutory guidance to the Care Act explains (para 6.65 – 6.72) the intention behind the 'whole family approach' and the obligations it places on authorities. This guidance has been augmented by 2015 good practice guidance.²⁰⁴

¹⁹⁹ See for example 'Guidance letter CI (95)12 Annex A para 1.1'.

²⁰⁰ 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'.

²⁰¹ HM Government *Working together to safeguard children* (2015) page 18.

²⁰² HM Government *Working together to safeguard children* (2015) page 18.

²⁰³ *Young Carers' (Needs Assessments) (England) Regulations 2015* SI 527, regulation 4(5).

²⁰⁴ Department of Health (et al.) *The Care Act and Whole-Family Approaches* (2015) pp. 8-9.

10.26 In summary the statutory guidance requires that authorities must:

- consider the ‘impact of the needs’ of the person cared for on family members (and others);
- identify any children who are involved in providing care;
- ‘where appropriate’ consider whether the child or young carer should be referred for a young carer’s assessment or a needs assessment under the Children Act 1989, or a young carer’s assessment under section 63 of the Care Act.
- ensure that adults’ and children’s care and support services work together – for example by sharing expertise and linking processes.
- (where it appears that a child is involved in providing care) consider:
 - the impact of the person’s needs on the young carer’s wellbeing, welfare, education and development;
 - whether any of the caring tasks the child is undertaking are inappropriate and if they are, should consider how supporting the adult with needs for care and support can prevent the young carer from undertaking this care. Inappropriate caring responsibilities are defined in the guidance (see para 10.36 below).

10.27 2015 guidance²⁰⁵ advises that a ‘whole-family approach’ would ensure that family-related questions are embedded in processes at first contact and subsequently, such as (page 3):

- Who else lives in your house?
- Who helps with your support and who else is important in your life?
- Is there anyone that you provide support or care for?
- Is there a child in the family (including stepchildren, children of partners or extended family)
- Does any parent need support in their parenting role?

10.28 It adds that whatever assessment process is being used/undertaken – in every case a question must be asked as to whether there are any children in the household and if they are undertaking any caring role (page 15).

Copies

10.29 Local authorities must provide the young carer, his or her parents, and any person they chose with a copy of the assessment.²⁰⁶ This requirement mirrors the duty to under the Care Act (both for adults in need and carers²⁰⁷ which in addition requires that they be provided with copies of their care and support plans²⁰⁸ which must be ‘in a format that is accessible to the person for whom the plan is intended’.²⁰⁹ While there is no explicit obligation in relation to young carers the relevant case law and general principles of public law must

²⁰⁵ Department of Health (et al.) *The Care Act and Whole-Family Approaches* (2015) pp 8-9.

²⁰⁶ Children Act 1989 17ZA(10).

²⁰⁷ The Care and Support (Assessment) Regulations 2014 reg 3(1) and see also para 6.98 of the statutory guidance to the Care Act 2014.

²⁰⁸ Care Act 2014 section 25(9) and (10).

²⁰⁹ Statutory guidance to the Care Act 2014 at para 10.87.

require that authorities do provide copies and that these be intelligible.²¹⁰

Care planning and the duty to provide support

- 10.30 Once a local authority has completed a young carers needs' assessment and (almost invariably) an assessment of the needs of the person for whom he or she provides care, the authority must then decide what support it is going to provide. This could take the form of support provided directly to the young carer and/or support for the person being cared for.
- 10.31 Where a young carer is undertaking inappropriate care, the local authority is under a duty to address this. It has discretion about whether to do this by providing care and support to the person being cared for or by providing support services directly to the young carer – but there is a duty to ensure that underlying problem (the inappropriate care) is addressed. As the former Commission for Social Care Inspection noted in this context 'some practitioners appear to think [incorrectly] the discretion is about whether to help carers'.²¹¹
- 10.32 If the authority decides that support should be provided to the young carer – the support will be under the Children Act 1989, section 17 whereas if provided to the person in need of care, it will generally be provided under the Care Act 2014 section 8 – unless the person in need of care is a child (in which case it will also – in general – be provided under the 1989 Act). These distinct obligations are considered separately below – and since most young carers provide care for adults,²¹² this situation will be reviewed first.

The provision of support under the Care Act 2014

- 10.33 As noted above, where an adult in need is being assessed under the Care Act 2014, his or her needs must be measured against the scale of eligibility set out in the relevant Eligibility Criteria regulations²¹³ (see para 4.11).
- 10.34 Regulation 2(2)(j) of these regulations provides that a significant impact on well-being that arises in consequence of an inability to carry 'any caring responsibilities the adult has for a child' may result in the adult being eligible for care and support services. In such situations (as research has suggested) the local authority should:

*'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.*²¹⁴

- 10.35 The statutory guidance to the Care Act 2014 reinforces this point, stressing

²¹⁰ See for example, *R v Islington LBC ex p Rixon* (1997–98) 1 CCLR 119 at 128, QBD.

²¹¹ Commission for Social Care Inspection (2008) *Cutting the cake fairly: CSCI review of eligibility criteria for social care*. CSCI, Newcastle para 3.22

²¹² About 70% – see para 10.1 above and C Dearden, and S Becker *Young Carers in the UK: The 2004 Report* (Carers UK and The Children's Society (2004)).

²¹³ The Care and Support (Eligibility Criteria) Regulations 2015 SI 313.

²¹⁴ Olsen, R. & Tyers, H. *Supporting disabled adults as parents* (2004) National Family and Parenting Institute Ref N34

that:

Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life... A local authority should consider how supporting the adult with needs for care and support can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities. Where a young carer is identified, the local authority must undertake a young carer's assessment under part 3 of the Children Act 1989 (para 2.50).

10.36 The statutory guidance (para 6.71²¹⁵) advises that when a 'local authority is determining whether the tasks a child carries out are inappropriate, it should also take into account the child's own view wherever appropriate'. The obligation to ensure that young carers do not undertake inappropriate care is picked up again at para 6.68 of the statutory guidance which advises that where an authority becomes aware that the child is carrying out such a caring role then the adult should be offered a needs assessment under the Care Act and the young carer an assessment under either the Care Act or the Children Act and whichever route is chosen the local authority must consider (para 6.69):

- the impact of the person's needs on the young carer's wellbeing, welfare, education and development;
- whether any of the caring responsibilities the young carer is undertaking are inappropriate.

10.37 As a result of such an assessment the authority must consider 'how supporting the adult with needs for care and support can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities' (para 6.71). Examples of the harm that may result to the young carer where there is a lack of support, include impaired access to education (e.g. regular absence from school or impacts upon their learning) and impaired ability to build relationships and friendships (para 6.71). The statutory guidance also provides examples of 'inappropriate caring responsibilities' including the young person (para 6.71):

- providing personal care such as bathing and toileting;
- carrying out strenuous physical tasks such as lifting;
- administering medication;
- maintaining the family budget;
- emotional support to the adult.

Supporting young carers under non-Care Act 2014 legislation

10.38 Where a young carer is caring for another child or young person (e.g. a sibling) then the necessary support provided by the local authority may not be capable of being provided under the Care Act 2014. In such situations the local authority will have to consider its duties to provide support either under the Children Act 1989, section 17 (which support can be provided,

²¹⁵ Department of Health (et al) *The Care Act and Whole-Family Approaches* (2015) p 34.

for example, to a disabled child, a young carer or a parent²¹⁶) or under the Chronically Sick and Disabled Persons Act 1970, section 2. Although disabled children (as with disabled adults) may be entitled to services under the Mental Health Act 1983, section 117, almost invariably any carers of that child will be supported by services being provided under the 1989 or 1970 Acts.²¹⁷

- 10.39 There will also be situations where a local authority may decide it is in the best interests of a young carer to provide services directly him or her. This will generally arise where the caring role is considered unavoidable – for example, the young carer is providing some support to a parent who is terminally ill and it is considered in his or her best interests to continue with this. In such situations the support would also, generally, be provided under the Children Act 1989, section 17.
- 10.40 Whenever it decided that services should be required – these should be ‘provided without delay’²¹⁸ – and, as the Working Together (2015)²¹⁹ guidance states:

A good assessment will monitor and record the impact of any services delivered to the child and family and review the help being delivered. Whilst services may be delivered to a parent or carer, the assessment should be focused on the needs of the child and on the impact any services are having on the child

- 10.41 As with care planning duties for adults (see para 5.44 above) support plans should be agreed with other professionals and the child and their family and ‘should set out what services are to be delivered, and what actions are to be undertaken, by whom and for what purpose’.²²⁰ They should also ‘be reviewed regularly to analyse whether sufficient progress has been made to meet the child’s needs and the level of risk faced by the child’.²²¹

The provision of support under the Children Act 1989, section 17

- 10.42 The Children 1989 Act, section 17ZC requires that the local authority, having undertaken a young carer’s needs assessment, decide whether any needs he or she has could be satisfied (wholly or partly) by services under the Act. Section 17 of the Act gives examples of the wide range of support services that can be provided under the Act – which may extend to providing accommodation and ‘giving assistance in kind or in cash’. Schedule 2 of the Act²²² contains an illustrative list of the range of services that can be provided to all children in need (i.e. including young carers):

²¹⁶ Children Act 1989, section 17(3).

²¹⁷ Disabled children who have been detained for treatment under the Mental Health Act 1983 may be entitled to support services under section 117 of that Act as well as under the 1989 and 1970 Acts. However since services under section 117(2) must be provided ‘for any patient’ (so detained) it is unlikely that they could encompass support services provided for a carer. For more detailed analysis of section 117 services see – Luke Clements, *Community Care and the Law*, 6th edition (Legal Action Group, 2015)

²¹⁸ HM Government *Working together to safeguard children* (2015) para 30.

²¹⁹ *Ibid.*

²²⁰ HM Government *Working together to safeguard children* (2015) para 53.

²²¹ HM Government *Working together to safeguard children* (2015) para 55.

²²² These are particularised in Schedule 2 Part 1 para 6 pursuant to section 17(2) of the Act

- a) advice, guidance and counselling;
- b) occupational, social, cultural or recreational activities;
- c) home help (which may include laundry facilities);
- d) facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under this Act or of any similar service;
- e) assistance to enable the child concerned and his family to have a holiday.

10.43 The Schedule also contains a requirement that where the support is required to address the needs of a disabled child then it must (among other things) assist the carer to continue to care ‘or to do so more effectively, by giving them breaks from caring’. This provision will seldom be relevant to young carers – where the duty will be to stop them undertaking inappropriate care – but may be relevant in transition assessments where a young carer is approaching 18 years of age. It is of considerable relevance to parent carers and considered below (para 11.14).

The provision of support under Chronically Sick and Disabled Persons Act 1970 (CSDPA), section 2

10.44 As noted above (see para 9.6), where a disabled child is being assessed and the local authority is satisfied it is necessary to meet their ‘needs’, it can do this by providing services under the CSDPA 1970, section 2. The section contains a lengthy list of services that can be provided – but it includes providing ‘practical assistance in the home’; games, outings, recreational facilities outside the home; holidays; adaptations/additional facilities in the home to secure the child’s safety, comfort or convenience; etc. Although these are all directed at the disabled child, rather than the young carer/parent carer, many of them can have direct benefits for such carers.

- ‘practical assistance’ will include – for example – a day sitting or night sitting service. This would ensure that the disabled child is safe but also have the associated benefit of giving the carer ‘a break’ – often referred to as respite or short break or replacement care.
- ‘recreational facilities outside the home’ will include – for example – an after school or holiday club or more general/routine arrangements whereby the disabled child is occupied and safe during which time the carers benefit from a break from their caring role.
- ‘holidays’ – can often constitute one of the best ‘breaks’ that disabled people and their carers can take. Where the carer’s attendance is necessary in order for a disabled person to have such a break (for instance as an escort) then this would also fall under the 1970 Act.²²³
- ‘adaptations/additional facilities in the home to secure the child’s safety’ – 2006 guidance²²⁴ explained that works under this heading may include ‘adaptations designed to minimise the risk of

²²³ *R v North Yorkshire CC ex p Hargreaves* (No 2) (1997–98) 1 CCLR 331, QBD.

²²⁴ Department for Communities and Local Government, *Delivering housing adaptations for disabled people: a good practice guide*, June 2006 Annex B para 18 and para 19.

danger where a disabled person has behavioural problems which causes him to act in a boisterous or violent manner, damaging the house, himself and perhaps other people' as well (for example) as enhanced alarm systems for people with hearing difficulties. Such support can of course be of immense benefit to all members of such a household.

Direct payments to carers for disabled people's services

- 10.45 Although a carer can be the recipient of a direct payment for services needed by a disabled child, once the 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 caused difficulties where the adult in need lacked the mental capacity to agree to the payment – due, for instance, to dementia or a profound learning disability. To address this difficulty, the Care Act section 32 enables local authorities to make direct payments to a third party (for example, a carer) in such cases. Guidance on the operation of this procedure is provided in the statutory guidance to the Care Act para 12.16. In general a local authority has the power to pay direct payments to someone on behalf of the adult in need where that third party agrees to the arrangement – although if the adult lacking capacity has appointed a Lasting Power of Attorney or has a Court of Protection appointed 'deputy' then slightly different procedures exist, albeit that there is still a local authority power to make such a payment.

Timescale for assessments

- 10.46 All assessments should be completed without delay and in this respect see the general comments at para 5.4 above. The statutory guidance relating to 'transition assessments' under the Care Act (see para 10.48 and 11.22 below) advises that they:²²⁵

should be carried out in a reasonable timescale. Local authorities should inform the young person or carer of an indicative timescale over which the assessment will be conducted and keep them informed.

- 10.47 Where a formal assessment is being undertaken under the Children Act 1989 (see para 10.18 below) the statutory guidance *Working Together (2015)*²²⁶ makes the following points/imposes the following obligations:

- The timeliness of an assessment is a critical element of the quality of that assessment and the outcomes for the child. The speed with which an assessment is carried out after a child's case has been referred into local authority children's social care should be determined by the needs of the individual child and the nature and level of any risk of harm faced by the child. This will require judgements to be made by the social worker in discussion with their manager on each individual case. Adult assessments, i.e. parent carer or non-parent carer assessments, should also be carried out in a timely manner, consistent with the needs of the child (para 57);

²²⁵ Statutory guidance to the Care Act 2014 at para 16.31.

²²⁶ HM Government *Working together to safeguard children (2015)*.

- Within one working day of a referral being received, a local authority social worker should make a decision about the type of response that is required and acknowledge receipt to the referrer (para 58);
- The maximum timeframe for the assessment to conclude, such that it is possible to reach a decision on next steps, should be no longer than 45 working days from the point of referral. If, in discussion with a child and their family and other professionals, an assessment exceeds 45 working days the social worker should record the reasons for exceeding the time limit (para 60);
- Whatever the timescale for assessment, where particular needs are identified at any stage of the assessment, social workers should not wait until the assessment reaches a conclusion before commissioning services to support the child and their family. In some cases the needs of the child will mean that a quick assessment will be required (para 61).

Young carers in ‘transition’ to adulthood

- 10.48 The Care Act 2014 sets out the responsibilities of local authorities for supporting carers and disabled children whose care and support needs will transfer to the adult social services. The Act has a formulaic approach to the duty – essentially that if it appears to an authority that (1) it is ‘likely’ that [a disabled child and/or the child’s carer/a young carer] will have care & support needs after transition; and (2) it will be of ‘significant benefit’ to be assessed – then the authority must assess or give reasons if it refuses to assess. Key terms in understanding this duty are ‘significant benefit’ and ‘likely to have needs’ – neither of which are defined in the Act.
- 10.49 The duty concerning young carers ‘in transition’ are found at sections 63 – 64 of the Act and such assessments are referred to as a ‘young carer’s assessment’. A ‘young carer’ has the same definition as in the Children Act 1989 (above) namely ‘a person under 18 who provides or intends to provide care for an adult (section 63(6)) but is not paid to provide the care or a formal volunteer (section 63(7)).
- 10.50 Chapter 16 of the statutory guidance to the Care Act provides considerable detail on the way authorities should approach their duties in relation to disabled children, the parents of disabled children and young carers.

Likely need

- 10.51 Para 16.9 of the statutory guidance advises that a young person or carer is ‘likely to have needs’ if they have ‘any likely appearance of any need for care and support as an adult’:

not just those needs that will be deemed eligible under the adult statute. It is highly likely that young people and carers who are in receipt of children’s services would be ‘likely to have needs’ in this context, and local authorities should therefore carry out a transition assessment for those who are receiving children’s services as they approach adulthood, so that they have information about what to expect when they become an adult.

Significant benefit

- 10.52 The statutory guidance (para 16.6) advises that it will generally be of ‘significant benefit’ to assess ‘at the point when their needs for care and support as an adult can be predicted reasonably confidently, but will also depend on a range of other factors’. In relation to young people with special educational needs (SEN) who have an Education, Health and Care (EHC) plan the guidance is unequivocal in stating that the transition assessment process should begin from Year 9²²⁷ (para 16.11), adding that even ‘for those without EHC plans, early conversations with local authorities about preparation for adulthood are beneficial’ (para 16.12).
- 10.53 Para 16.7 gives further guidance as to the point at which the young person’s needs for care and support (as an adult) can be predicted reasonably confidently, stating:
- Transition assessments should take place at the right time for the young person or carer and at a point when the local authority can be reasonably confident about what the young person’s or carer’s needs for care or support will look like after the young person in question turns 18. There is no set age when young people reach this point; every young person and their family are different, and as such, transition assessments should take place when it is most appropriate for them.*
- 10.54 Para 16.10 states that the considering of ‘significant benefit’ is ‘not related to the level of a young person or carer’s needs, but rather to the timing of the transition assessment’. It then provides an illustrative list of factors that should be considered when trying to establish the right time to assess - namely:
- The stage they have reached at school and any upcoming exams;
 - Whether the young person or carer wishes to enter further/higher education or training;
 - Whether the young person or carer wishes to get a job when they become a young adult;
 - Whether the young person is planning to move out of their parental home into their own accommodation;
 - Whether the young person will have care leaver status when they become 18;
 - Whether the carer of a young person wishes to remain in or return to employment when the young person leaves full time education;
 - The time it may take to carry out an assessment;
 - The time it may take to plan and put in place the adult care and support;
 - Any relevant family circumstances;
 - Any planned medical treatment.
- 10.55 An informative case study is provided in the guidance (para 16.15) concerning the timing of a transition assessment. It concerns a 15-year-old disabled child who attends an education funded residential school and who also

²²⁷ Department of Health *SEN Code of Practice Preparing for Adulthood* (2014) para 88.11.

receives a funding package from social services – both at the school and on the weekends/holidays with her parents. The parents request a transition assessment on her 16th birthday. After a discussion with the family the local authority realises that when the young person leaves school at 19 ‘it will not be appropriate for her to live with her parents and she will require substantial supported living support and a college placement’. The local authority then appreciates that this will necessitate ‘a lengthy transition in order to get used to new staff, a new environment and a new educational setting’ not least because the ‘college has also indicated that that they will need up to a year to plan for her start’. On this basis the local authority concludes that it would be of ‘significant benefit’ for the transition assessment to take place.

- 10.56 The Care Act 2014 section 67 provides significant rights to advocacy support for individuals who (but for the support) would experience substantial difficulty in taking part in their assessment, care review etc. The obligation does not arise if the authority is satisfied that there is some other ‘appropriate’ person who can provide the support (section 67(5)). As para 7.2 to the statutory guidance to the Care Act explains, this duty ‘also applies to children who are approaching the transition to adult care and support, when a child’s needs assessment is carried out, and when a young carer’s assessment is undertaken’.

Young carers not receiving children’s services

- 10.57 Transition planning should consider, not only the sustaining of the care and support needs of disabled young people and carers – but also ‘how carers’, young carers’ and other family members’ needs might change’ – the example given being (para 16.20):

... some carers of disabled children are able to remain in employment with minimal support while the child has been in school. However, once the young person leaves education, it may be the case that the carer’s needs for support increase, and additional support and planning is required from the local authority to allow the carer to stay in employment.

- 10.58 In this context, the guidance (para 16.21) requires social services to be aware of the SEN code of practice relating to the transition arrangements for disabled young people and the importance of them gaining access to full-time programmes. It notes however that such an option may not be suitable or available for all young people and advises that in addition the authority should consider ‘other provision and support ... such as volunteering, community participation or training’.

Continuity of support for young carers in transition (section 66)

- 10.59 The Care Act 2014, section 66 creates a complex set of provisions²²⁸ designed to ensure that once the young carer or disabled child reach 18, that the local authority provides the care and support it identified as necessary in its ‘transition’ assessment. It also enables local authorities to continue

²²⁸ These are delivered by inserting in the CA 1989 new sections (s17ZB and s17ZC) and also by amending the Chronically Sick and Disabled Persons Act 1970 by adding a new s2A.

providing support under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 even though the child has reached 18. Accordingly, assessments of disabled children/young carers that take place before the young people become 18, will either continue to apply when they become 18 until reviewed²²⁹ or if the local authority decides not treat the assessments as a continuing obligation – then it must continue with any support it has been providing until it has undertaken a reassessment.²³⁰

Transition assessments – general provisions

- 10.60 The statutory guidance to the Care Act at chapter 16 provides general guidance on the nature and scope of transition assessments: guidance that is applicable to young carers, parent carers and disabled young people. In this section the paragraph numbers relate to this guidance.
- 10.61 All transition assessments should be person centred (para 16.29); consider how the needs of young people and carers might change during the transition process (para 16.20); consider immediate short-term outcomes/medium and longer-term aspirations (para 16.34); and identify (para 16.25 - 16.26):
- current needs for care and support and how these impact on wellbeing;
 - whether the carer is likely to have needs for care and support after the child in question becomes 18;
 - if so, what those needs are likely to be, and which are likely to be eligible needs;
 - the outcomes the carer wishes to achieve in day-to-day life and how care and support (and other matters) can contribute to achieving them.
 - whether the carer:
 - is able to care now and after the child in question turns 18;
 - is willing to care now and will continue to after 18;
 - works or wishes to do so;
 - is or wishes to participate in education, training or recreation.
- 10.62 After completion of the assessment the authority is required to indicate which needs are likely to be eligible needs once the young person turns 18 ‘to ensure that the young person or carer understands the care and support they are likely to receive and can plan accordingly’ (para 16.51).
- 10.63 Local authorities are not obliged to move responsibility from children’s social care to adult care once the young person becomes 18. The statutory guidance expresses the view that in general this move will often begin ‘at the end of a school term or another similar milestone, and in many cases should be a staged process over several months or years’ (para 16.62).

²²⁹ I.e. be treated as a carer’s assessment under the Care Act 2014 section 64(7).

²³⁰ For a more detailed explanation as to the effect of section 66 – see S Broach, L Clements and J Read ‘*Disabled Children: A Legal Handbook*’ 2nd edition (Legal Action Group 2015).

Continuity of care after the age of 18

- 10.64 The statutory guidance points to the distress and disruption that can be caused by there being a shortfall in services when a young person becomes the responsibility of the adult services – and in forthright terms states: ‘local authorities must not allow a gap in care and support when young people and carers move from children’s to adult services’ (para 16.67). If at the transition stage adult services have not put in place care and support the authority ‘must continue providing services until the relevant steps have been taken, so that there is no gap in provision’ (para 16.68). ‘Relevant steps’ in this context mean that the authority has conducted a transition assessment and as a result has determined the person’s needs for adult care and support (if any) (para 16.68- 69).

Cooperation between adult and children’s services

- 10.65 As also noted above (para 7.13) the Children Act 1989 Act, section 27 provides authorities with a significant power to request the co-operation in specific cases of the authority’s ‘relevant partners’ (such as housing authorities, the NHS, police, probation etc.): a power that includes requests relating to the support needs for disabled children and their carers. The Care Act 2014 in addition places a duty on a local authority’s adult and children’s services officers to co-operate (section 6(4)²³¹) with a view ‘in particular’ to ‘smoothing the transition’ for young carers, disabled children and their adult carers (section 6(6)(c). In this context the statutory guidance at para 16.42 requires that authorities:

have a clear understanding of their responsibilities, including funding arrangements, for young people and carers who are moving from children’s to adult services. Disputes between different departments within a local authority about who is responsible can be time consuming and can sometimes result in disruption to the young person or carer.

Transition assessments – carers’ education and work aspirations

- 10.66 In relation to the transition assessment statutory guidance notes that:
- many young carers ‘feel that they cannot go to university or enter employment because of their caring responsibilities. Transition assessments and planning must consider how to support young carers to prepare for adulthood and how to raise and fulfil their aspirations’ (para 16.23); and
 - caring responsibilities could have an impact on siblings’ school work, or their aspirations to go to university. Young carers’ assessments should include an indication of how any care and support plan for the person(s) they care for would change as a result of the young carer’s change in circumstances. For example, if a young carer has an opportunity to go to university away from home, the local authority should indicate how it would meet the eligible needs of any family members that were previously being met by the young

²³¹ See also the Children Act 2004, section 10 which requires authorities to make arrangements to promote cooperation between relevant partners (i.e. NHS, housing authorities, police, probation etc).

carer' (para 16.24).

- in the context of carers wishing to return to or remain in work 'some sixth forms or colleges offer five-day placements which allow parents to remain in employment full-time. However, for young people who do not have this opportunity ... transition assessments should consider if there is other provision and support for the young person such as volunteering, community participation or training which not only allows the carer to remain in full-time employment, but also fulfils the young person's wishes or equips them to live more independently as an adult' (para 16.22).

10.67 The National Institute of Adult Continuing Education (NIACE) has produced useful guidelines concerning young adult carers in relation to training and work.²³²

²³² See NIACE *Access and Inclusion: Young Adult Carers and Education and Training* (2013) and NIACE *Supporting young adult carers to access learning* (2013)

11. Parent carers

- 11.1 The Children Act 1989²³³ defines a ‘parent carer’ as an adult ‘who provides or intends to provide care for a disabled child for whom the person has parental responsibility’.²³⁴ As will be seen below (see para 11.11) this definition does not cover those carers (e.g. adult relatives) who do not have parental responsibility – and their rights are addressed separately by the legislation.
- 11.2 ‘Parent carers’ were not mentioned in any legislation prior to the enactment of the Children and Families Act 2014. As a consequence some authorities had been reluctant to undertake separate carers’ assessments of parents who were caring for a disabled child. This failure was generally unlawful since the Carers (Recognition and Services) Act 1995 section 1 placed (and continues to place – see para 11.11 below) a duty on authorities to assess all carers (regardless of their age) who were providing substantial amounts of care on an unpaid basis: a duty referred to on a number of occasions by the courts and Ombudsman.²³⁵ Through amendment the 2014 Act now places significant additional responsibilities on authorities towards ‘parent carers’.

Strategic obligations

- 11.3 The Children Act 1989, section 17ZD(14) requires authorities to take reasonable steps to identify the extent to which there are parent carers within their area who have needs for support.

Duty to co-operate

- 11.4 As noted above (see para 7.12) the duty under the Care Act 2014, section 6 on local authorities to co-operate with their ‘relevant partners’ (such as housing authorities, the NHS, police, probation etc.) is augmented by a power in section 7 that enables them to request the co-operation in specific cases: a power that includes requests relating to the support needs of a ‘carer of a child’.

Duty to assess

- 11.5 The Children Act 1989 sections 17ZD and 17ZE²³⁶ oblige local authorities to assess parent carers²³⁷ on the ‘appearance of need’ – i.e. if it appears

²³³ Section 17ZA(3) inserted by Children and Families Act 2014, section 96

²³⁴ Children Act 1989, section 17ZD(2) and see para 9.3 above for the definition of a ‘disabled child’.

²³⁵ *R (LH and MH) v Lambeth LBC* [2006] EWHC 1190 (Admin) 25 May 2006; *HN (A Minor)* [2010] NIQB 86 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; 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.

²³⁶ Provisions inserted by the Children & Families Act 2014, section 97.

²³⁷ Referred to in the Care Act 2014 as ‘child’s carers’ – sections 60 – 62 see above.

to a local authority that a parent carer may have needs for support (or is requested by the parent). Such assessments are referred to as ‘parent carer’s needs assessments’. Having undertaken such an assessment the authority must then determine whether the parent has needs for support and, if so, what those needs are.

- 11.6 Parent carer’s needs assessments must include ‘an assessment of whether it is appropriate for the parent carer to provide, or continue to provide, care for the disabled child, in the light of the parent carer’s needs for support, other needs and wishes’²³⁸ and must also have regard to:²³⁹
- the well-being of the parent carer (‘well-being’ has the same meaning as the Care Act 2014 Part1), and
 - the need to safeguard/promote the welfare of the disabled child and any other child for whom the parent carer has parental responsibility.
- 11.7 The requirement to consider ‘well-being’ brings with it the duty of the authority to consider (among other things) the parent carers’ (a) personal dignity; (b) physical and mental health and emotional well-being; (c) protection from abuse and neglect; (d) control by the individual over day-to-day life (including over care and support, or support provided to the individual and the way in which it is provided); (e) participation in work, education, training or recreation; (f) social and economic well-being; (g) domestic, family and personal relationships; (h) suitability of living accommodation; (i) the individual’s contribution to society.
- 11.8 This obligation replicates and broadens the pre-Care Act duty in the Carers (Recognition & Services) Act 1995, section 1(2C)²⁴⁰ to consider whether the carer: (i) works or wishes to work; or (ii) is undertaking, or wishes to undertake, education, training or any leisure activity. This restatement of the pre-Care Act law means that previous case law and Ombudsman’s reports will remain relevant to the new duty (and as noted below, section 1 of the 1995 Act remains in force – see para 11.11). A key Ombudsman’s report²⁴¹ in this context concerned a parent who sought Direct Payments to enable him to purchase respite care so that he could pursue his university 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’.
- 11.9 The legislation provides for a parent carer’s assessment to be combined with other assessments – i.e. the assessment of the disabled child’s needs (section 17ZE(3)) and (as noted above in relation to young carers) the guidance gives emphasis to assessments adopting ‘whole family approach’ – see para 10.23.

Copies

²³⁸ Children Act 1989, section 17ZD(9).

²³⁹ Children Act 1989, section 17ZD(10).

²⁴⁰ Inserted by Carers (Equal Opportunities) Act 2004, section 2.

²⁴¹ Public Service Ombudsman (Wales) Complaint No. B2004/0707/S/370 against Swansea City Council 22 February 2007 see in particular paras 78, 133 & 137.

- 11.10 Local authorities must provide parent carers and any person they chose with a copy of the assessment.²⁴² This requirement mirrors the duty to under the Care Act (both for adults in need and carers²⁴³) which in addition requires that they be provided with copies of their care and support plans²⁴⁴ which must be ‘in a format that is accessible to the person for whom the plan is intended’.²⁴⁵ While there is no explicit obligation in relation to parent carers the relevant case law and general principles of public law must require that authorities do provide copies and that these be intelligible.²⁴⁶

Carers of disabled children who do not have ‘parental responsibility’

- 11.11 Neither the Children and Families Bill nor the Care Bill as initially published contained any provisions addressing the rights of young carers and parent carers (although the Care Bill made provision for ‘transition into adulthood’ assessments). As a result of a sustained campaign by carers’ organisations 11th hour amendments were made to the Bill that became the Children and Families Act 2014: amendments that appeared to have addressed the problems that would have resulted from this omission. Unfortunately, on analysis, this proved to be mistaken in relation to the amendments that sought to secure the position of people caring for disabled children.²⁴⁷ As noted above the Children and Families Act 2014 provides improved protection for those who care for a disabled child for whom they have parental responsibility.²⁴⁸ As a consequence a grandparent, adult sibling, relative or a friend providing care would have had no rights to an assessment or support – as well as some unmarried fathers and some step-parents. The omission of such carers was clearly unintended – not least because the statutory guidance to the Care Act highlights the importance of support for people such as grandparents who are providing care²⁴⁹ – but of course this provision (in the Care Act) is predicated on them also caring for an adult.
- 11.12 The problem has been resolved by a decision not to repeal the relevant provisions of the Carers (Recognition and Services) Act 1995 (section 1) that provide for the assessment of (non-parental) carers of disabled children.²⁵⁰ The effect is that local authorities owe a duty to all carers of disabled children (although a similar exclusion applies to those who provide the care as part of their employment or as formal volunteers²⁵¹). The obligation in relation to

²⁴² Children Act 1989 section 17ZD(13).

²⁴³ The Care and Support (Assessment) Regulations 2014 reg 3(1) and see also para 6.98 of the statutory guidance to the Care Act 2014.

²⁴⁴ Care Act 2014 section 25(9) and (10).

²⁴⁵ Statutory guidance to the Care Act 2014 at para 10.87.

²⁴⁶ See for example, *R v Islington LBC ex p Rixon* (1997–98) 1 CCLR 119 at 128, QBD.

²⁴⁷ Children & Families Act 2014, section 97 which amends the Children Act 1989, inserting section 17ZD – subsection (2) of which defines a parent carer as an ‘adult who provides or intends to provide care for a disabled child for whom the person has parental responsibility’ Children Act 1989, section 17ZD(2).

²⁴⁸ Parental responsibility (PR) is a legal status governed by the Children Act 1989 section 3(1). All mothers and most fathers have legal PR. For an overview of the law concerning PR see Manjit Gheera *Parental responsibility* House of Commons Library Briefing Note 8 September 2014. *Some unmarried fathers of children lack parental responsibility – in the absence of an agreement or court order and this is also the case for some step parents.*

²⁴⁹ See for example, Department of Health *Care and Support statutory guidance* para 6.128 (DH 2014)

²⁵⁰ See *The Care Act 2014 and Children and Families Act 2014 (Consequential Amendments) Order 2015*. This is however only a short-term ‘patch’: the 1995 Act creates a higher assessment threshold for carers than does the Children Act 1989 section 17ZD – albeit that in practice little will run on this distinction.

²⁵¹ Carers (Recognition & Services) Act 1995 section 1(3)

the assessment process of such carers is as wide ranging as that for those with ‘parental responsibility’ and (as 2015 guidance²⁵² makes clear) requires consideration as to

whether the carer works or wishes to work, or whether they wish to engage in any education, training or recreation activities. The local authority then has to take the assessment into account when deciding whether to provide any services to the disabled child.

Support services

- 11.13 Having undertaken a parent carer’s or other carer’s assessment, the local authority must then decide whether the parent has needs for support; whether the disabled child has needs for support; and if so whether those needs could be satisfied (wholly or partly) by services under Children Act 1989, section 17. The parent must be given a written copy of the assessment (s17ZD(13)).
- 11.14 Reference is made to paras 10.42 – 10.44 above which describe the wide range of services that can be provided under the 1989 Act and also the Chronically Sick and Disabled Persons Act 1970, section 2 which can either support the carer directly (in the case of the 1989 Act) or indirectly (in the case of both the 1989 and 1970 Acts). In this context the emphasis in Schedule 2 of the 1989 Act²⁵³ is of particular relevance – namely that services must be designed to: minimise the effect of the child’s disabilities; give them the opportunity to lead lives which are as normal as possible; and ‘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’.
- 11.15 Emphasis is given to the importance of appropriate services in chapter 4 of the statutory guidance to the Care Act. At para 4.26 it is noted that:

some parent carers need extra support to juggle caring and paid work after their child leaves full time education. Loss of paid employment can have a significant impact on the carer’s wellbeing and self-esteem as well as a significant impact on the family’s financial circumstances. Similar issues can affect young carers. Taking a whole family approach to care and support planning that sets out a “five-day offer” or appropriate supported living options for a young person, and support for a carer to manage an increased caring role (that allows them to stay in paid work if they wish to do so) can help families manage the transition and save money by avoiding unwanted out-of-county placements.

Respite/short break care & disabled children

- 11.16 The Government’s report *Aiming High for Disabled Children: Better Support for Families* (2007)²⁵⁴ highlighted the importance of short breaks in reducing the

²⁵² Department of Health (et al) *The Care Act and Whole-Family Approaches* (2015) p.16 - and see also *HM Government Working together to safeguard children* (2015) para 27.

²⁵³ Schedule 2 Part 1 para 8 pursuant to section 17(2) of the Act

²⁵⁴ HM Treasury & the Department for Education and Skills (2007) at para 4.2.

‘high levels of stress’ present in many families with disabled children, stress that might otherwise ‘result in family breakdown.’

11.17 As a consequence the Children Act 1989²⁵⁵ was amended to include a requirement that social services authorities ‘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 has been the subject of detailed regulations²⁵⁶ and guidance.²⁵⁷

11.18 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.

11.19 The guidance (at page 5) 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;
- 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.

Charging and disabled children’s services

11.20 The Children Act 1989 permits local authorities to make charges for services provided for disabled children²⁵⁸ and to include their parents’ means in

²⁵⁵ By the Children and Young Persons Act 2008 section 25, inserting a new paragraph into Schedule 2 – namely para 6 (c).

²⁵⁶ The Breaks for Carers of Disabled Children Regulations 2011 No. 707.

²⁵⁷ Department for Education (2011) *Short Breaks for Carers of Disabled Children: Advice to local authorities*.

²⁵⁸ Section 29 Children Act 1989 in relation to community based services and CA 1989 Sch 2 Part III in relation to residential care placements.

arriving at such charges. As with adults, this guide does not address the charging rules in detail,²⁵⁹ but the following points are of general relevance.

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

Parent carers of disabled children in transition

11.22 In much the same way as the Care Act places duties on local authorities to assess the needs of young carers (see para 10.48 above) and disabled children²⁶⁰ who are ‘in transition’ into adulthood – so too does it oblige authorities to assess the likely needs of the adult carers of disabled children (referred to as a ‘child’s carer’) during the child’s transition (sections 60 – 62). In simple terms²⁶¹ the Act provides that a local authority must undertake a needs assessment of the carer of a disabled child if it considers that the carer is likely to have needs for support after the child becomes 18 and that the assessment would be of significant benefit to the carer. Such an assessment is referred to as a ‘child’s carer’s assessment’. If a local authority decides not to undertake such an assessment it must give reasons for its refusal. See discussion above (para 10.51 – 10.56) as to how ‘significant benefit’ and ‘likely to have needs’ should be construed.

11.23 A child’s carer is defined as ‘an adult (including one who is a parent of the child) who provides or intends to provide care for the child’ (section 61(7)) but is not paid to provide the care or a formal volunteer (section 61(8)).

11.24 Such an assessment will generally occur at the same time as the disabled child is having his or her transition assessment. The requirements of the transition assessment are in most respects the same as those for young carers and disabled young people in transition and are analysed at para

²⁵⁹ 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.

²⁶⁰ Care Act 2014, sections 58 & 59.

²⁶¹ The Act, again, contains overly complicated provisions on the issue of consent/capacity to consent and what must be included in the assessment – see footnote above.

10.60 above.

Continuity of support for a parent carer whose child is in transition

- 11.25 As with the case of young carers (see para 10.59) the Care Act 2014, section 66 creates a complex set of provisions²⁶² designed to ensure that once the disabled child reaches 18, the local authority provides the parent carer with the support it has identified as necessary in its ‘transition’ assessment. It also enables local authorities to continue providing support to the parent carer under the Children Act 1989 even though the child has reached 18 and that assessments that took place before that date, will either continue to apply when the young person becomes 18 (until reviewed²⁶³), or if the local authority decides not to treat the assessments as a continuing obligation – then it must continue with any support it has been providing until it has undertaken a reassessment.²⁶⁴
- 11.26 As noted above in the context of young carers (para 10.57) transition planning should consider, not only the sustaining of the care and support needs of disabled young people and carers – but also ‘how carers’, young carers’ and other family members’ needs might change’ – the example given being in the statutory guidance (para 16.21):
- ... some carers of disabled children are able to remain in employment with minimal support while the child has been in school. However, once the young person leaves education, it may be the case that the carer’s needs for support increase, and additional support and planning is required from the local authority to allow the carer to stay in employment.*
- 11.27 In this context, the statutory guidance (para 16.22) requires social services to be aware of the SEN code of practice relating to the transition arrangements for disabled young people and the importance of them gaining access to full-time programmes. It notes however that such an option may not be suitable or available for all young people and advises that in addition the authority should consider ‘other provision and support ... such as volunteering, community participation or training’.

Childcare Act duties

- 11.28 The Childcare Act 2006, section 6 requires local authorities 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

²⁶² These are delivered by inserting in the CA 1989 new sections (s17ZB and s17ZC) and also by amending the Chronically Sick and Disabled Persons Act 1970 by adding a new s2A.

²⁶³ I.e. be treated as a ‘child’s carer’s assessment’ under the Care Act 2014 section 61(6).

²⁶⁴ For a more detailed explanation as to the effect of section 66 – see S Broach, L Clements and J Read ‘Disabled Children: A Legal Handbook’ 2nd edition (Legal Action Group 2015).

childcare that is suitable for disabled children.

- 11.29 The courts have held that a decision by a local authority to reduce its funding of nursery or other child care arrangements will be unlawful if it has not had proper regard to its duties under the 2006 (to secure childcare sufficient to meet the requirements of parents in the area to enable them to work or undertake education or training).²⁶⁵

²⁶⁵ See *R (West and others) v. Rhondda Cyon Taf CBC* [2014] EWHC 2134 (Admin) – the court also considered that the local authority had failed to have regard to the impact these changes would have on its general duties under s17 Children Act 1989.

12. Carers and specific categories of service users

Carers and mental health service users

- 12.1 People with mental health difficulties are entitled to a Care Act or Children Act assessment of their needs in common with other adults in need/disabled children. 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 – i.e. regardless of whether or not the patient has been detained under the Mental Health Act 1983 (MHA 1983).
- 12.2 Because of concern about the low rate of carers’ assessments within the mental health services²⁶⁶ the Department of Health’s 1999 National Service Framework for Mental Health²⁶⁷ 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,
 - have the assessment 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 difficulty enjoy. 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 2014 or 1989 Acts.
- 12.4 The rationale behind Standard 6 is explained in the following terms:²⁶⁸
- 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.²⁶⁹ It requires social services to draw up a care plan and

²⁶⁶ Social Services Inspectorate. *Still Building Bridges* (The Stationery Office, London, 1999)

²⁶⁷ Department of Health *A National Service Framework for Mental Health: Modern Standards & Service Models* (1999).

²⁶⁸ A National Service Framework for Mental Health (as above) page 69

²⁶⁹ A National Service Framework for Mental Health (as above) page 72.

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.

People who have been detained for treatment under the MHA 1983

12.6 The statutory guidance to the Care Act is brief in relation to the Act's relevance for carers of people detained under the 1983 Act. At para 6.77 (in the context of 'Integrated assessments' – i.e. assessments for people who 'have needs that are met by various bodies') it is stated:

A local authority may carry out a needs or carer's assessment jointly with another body carrying out any other assessment ... provided that person agrees... An integrated approach may ... include putting processes in place to ensure that the person is referred for other assessments such as an assessment for after-care needs under the Mental Health Act 1983.

12.7 In the care planning section of the guidance, reference is made (at para 10.9) to care plans meeting the needs identified under sections 18 – 20 of the Care Act 2014, adding:

Where a local authority is required to meet needs under section 117 of the Mental Health Act 1983 this chapter should be read in conjunction with chapter 34 of the "Mental Health Act 1983 Code of Practice" [2014] (on the Care Programme Approach) and "Refocusing the Care Programme Approach" [2008].

12.8 The lack of a clear 'read across' between the Acts is also evident in the (2014) Code of Practice for the 1983 Act, which fails to make it clear that the Care Act applies to carers of people who have been detained. This must however be the case, given how much more widely 'carer' has been defined.²⁷⁰

12.9 As noted above, the 11th hour amendments to the Children and Families Act 2014 to protect the rights of people caring for disabled children resulted

²⁷⁰ See above: i.e. that carers no longer need to be providing (or intending to provide) substantial amounts of care on a regular basis (section 10(3)).

in unforeseen problems. One of these concerned people without parental rights who were caring for a disabled child whose support needs were being provided under section 117 of the 1983 Act. To fill this legislative lacuna – the Carers (Recognition & Services) Act 1995, section 1 has been amended to make it clear that they too have a right to an assessment of their needs as carers.

Carers of people with ‘long-term’ conditions.

12.10 The National Service Framework (NSF) for Long-term Conditions (2005)²⁷¹ sets out a number of ‘Quality Requirements’ for the care of those suffering from long-term neurological conditions and their carers. Long-term conditions are defined as including conditions such as epilepsy, multiple sclerosis, motor neurone disease, Parkinson’s disease, post-polio syndrome, cerebral palsy and acquired brain injury (however strokes are covered in the NSF for Older People).

12.11 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 role including how to move and handle the cared-for person and how to use equipment to help in daily living;
- carers are given the opportunity to work in partnership with specialist teams.

3. A range of flexible, responsive and appropriate services is provided for all carers which:

- deals effectively with emergency situations;
- can support highly dependent people at short notice;
- provides appropriate support for children in the family;
- provides carers with breaks across a range of settings;

²⁷¹ Department of Health (March 2005)

- is culturally appropriate (e.g. 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

- 12.12 People who misuse drugs or alcohol, are entitled to social care support services. For the purposes of the Care Act they are adults ‘in need’ and the Eligibility Criteria requirement that the person have a ‘physical or mental impairment or illness’ (see para 4.12 above) which the statutory guidance at para 6.102 explains, includes conditions that result from ‘physical, mental, sensory, learning or cognitive disabilities or illnesses, substance misuse or brain injury’. It follows that a person who cares for someone misusing drugs or alcohol is entitled to a carer’s assessment – just like any other qualifying carer.
- 12.13 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 and/or via agreements with the NHS to Mental Health teams (as between a third to a half of people with severe mental health problems have substance misuse related problems²⁷²). If councils continue to do this, they will need to ensure that the delegation agreement specifically addresses: the duty to undertake carers’ assessments; the mechanism by which carers eligible needs are met; the obligation to identify and to respond to the needs of any children or young people who may be young carers.
- 12.14 Guidance has made some (but inadequate) steps to addressing this oversight. These include:
- The Home Office Action Plan for 2008 - 2011²⁷³. 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):

²⁷² Department of Health (2002), *Mental health policy implementation guide dual diagnosis good practice guide*, para 1.3.1.

²⁷³ Home Office *Drugs: protecting families and communities Action Plan 2008–2011* (2008).

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 Strategy²⁷⁴ (which suffers from the same limitations as the Action Plan above) it nevertheless states at page 6 that its aim is to 'involve 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, s242.²⁷⁵

²⁷⁴ Home Office *Drugs: protecting families and communities The 2008 drug strategy* (2008)

²⁷⁵ As amended by s233 Local Government and Public Involvement in Health Act 2007 (formerly s11 Health and Social Care Act 2001).

13. Carer and service user conflict

- 13.1 Not infrequently the interests of a carer and the person cared for may appear to conflict. In such cases the law is seldom of assistance – save only to assert that both adults in need and carers have ‘rights’. How these are reconciled will almost always be a matter of judgment requiring an understanding of the needs and interests of both parties: time, imagination and perseverance.
- 13.2 The obligation to meet the needs of a carer in such cases must comply with the law – and as noted above (para 5.38), the Care Act 2014, section 20(8) requires that where a local authority has identified that a carer has eligible needs ‘but it does not prove feasible for it to’ [meet those needs] ‘by providing care and support to the adult needing care, it must, so far as it is feasible to do so, identify some other way in which to do so’.
- 13.3 Previous guidance²⁷⁶ has advised that in such cases of disagreement between the person cared for 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’.
- 13.4 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.²⁷⁷
- 13.5 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

²⁷⁶ Department of Health Circular ‘Community Care Directions 2004’ LAC (2004) 24 para 2.4.

²⁷⁷ See for instance *R v Kensington & Chelsea RLBC ex p Kujtim* (1999) 2 CCLR 340 at 354I and *R (Patrick) v. Newham LBC* (2000) 4 CCLR 48.

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?

- 13.6 The 2015 practice guidance on whole family approaches²⁷⁸ provides practical advice concerning an elderly person with dementia who was adamant that she only wanted her daughter to care for her – and who was herself ‘exhausted and at breaking point’ – to which an imaginative approach was taken to work around this issue.

Exclusion from services

- 13.7 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 report²⁷⁹ the Ombudsman cited with approval the following reference in the 2001 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...*²⁸⁰

²⁷⁸ Department of Health (et al) *The Care Act and Whole-Family Approaches* (2015) pp. 8-9.

²⁷⁹ Complaint No 03/C/16371 against Stockton-on-Tees Borough Council 18 January 2005 paragraph 13.

²⁸⁰ *Valuing People*, paragraph 5.7 and see also Circular HSC 2001/016: LAC(2001)23 paragraph s 37 & 38.

14. Carers equality and human rights

- 14.1 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 has also recognised how central considerations of equality and human rights are to the situation of carers. In its 2010 Equality Review²⁸¹ it highlighted (as one of its five key 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 the huge contribution that unpaid carers make to the economy (which has been estimated at £132 billion each year²⁸²), the Report stressed the need for a reform of the state’s economic and social approaches to caring.
- 14.2 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

- 14.3 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).
- 14.4 For a general review of the international perspective concerning the human rights of carers – reference should be made to:
- The 2013 UN report ‘Focusing on women caregivers’ by Magdalena Carmona²⁸³ which observed that ‘it is hard to think of a human right that is not potentially affected in some way by the unequal distribution and difficulty of unpaid care work’; and
 - The 2013 paper by Luke Clements ‘Does Your Carer Take Sugar?’²⁸⁴ which provides a global overview of the ‘carers rights movement’.
- 14.5 In the European context, however, Article 8 of the European Convention on Human Rights (ECHR) places an obligation on public bodies to ‘respect’ the

²⁸¹ Equality and Human Rights Commission (2010) *How fair is Britain?* Executive Summary p46.

²⁸² Carers UK and University of Leeds, *Valuing Carers* (2015).

²⁸³ The UN General Assembly’s Special Rapporteur on extreme poverty and human rights, (Extreme poverty and human rights Report of 68th Session GA, A/68/293 (UN, 2013).

²⁸⁴ *Washington and Lee Journal of Civil Rights and Social Justice* (2013) Volume 19 pp 397 – 434.

private and family lives of individuals. The duty (which is part of our domestic law – as a result of the Human Rights Act 1998) has been held to include a number of elements, for example a duty to refrain from unnecessary 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’.

- 14.6 The obligation of ‘non-interference’ was explained by Lord Justice Munby in a 2010 judgment²⁸⁵ 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...

- 14.7 The Ombudsman has also expressed concern about heavy handed action by councils. A 2008 complaint²⁸⁶ 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 complaint²⁸⁷ 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 ‘breathtaking 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.
- 14.8 *R (Hughes) v Liverpool City Council* (2005)²⁸⁸ 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

²⁸⁵ *A Local Authority v A (A Child)* [2010] EWHC 978 (Fam).

²⁸⁶ Complaint no 07/B/07665 against Luton Borough Council, 10 September 2008.

²⁸⁷ Complaint no 07/C/03887 against Bury MBC, 14 October 2009.

²⁸⁸ [2005] EWHC 428 (Admin) 8 CCLR 243 paras 35 - 39.

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)²⁸⁹ (para 100) which makes (amongst other things) specific mention of the Liverpool case in this context.

- 14.9 *In R (A & B, X & Y) v. East Sussex County Council* (2003)²⁹⁰ 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*²⁹¹ 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

- 14.10 It is not only the ECHR that is relevant to European human rights claims concerning carers. In *FIDH v. Belgium* (2013)²⁹² the European Committee of Social Rights – in finding a violation of Article 16 of the European Social Charter²⁹³ due to Belgium’s inadequate community care provision for highly dependent people living with their families – referred to the consequential ‘far-reaching negative implications for the family’s living conditions in many cases’ and that for ‘many parents the painful consequence of their devotion to a child with a permanent health problem is that they have to give up work altogether or reduce their working hours to take care of their highly dependent family member’ (para 184). The Committee stressed the substantial obligations that rested with states (to make adequate provision) because of the impact a failure to make provision had, not only on ‘persons with disabilities’ but also on ‘their families on whom falls the heaviest burden in the event of institutional shortcomings’ (para 185).²⁹⁴

Carers and the Equality Act 2010

- 14.11 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 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.

²⁸⁹Department of Health (2010).

²⁹⁰ [2003] EWHC 167 (2003) 6 C.C.L. R. 194 at para 116.

²⁹¹ [2002] EWHC 2282 (Admin); (2002) 5 CCLR 577 at [33]

²⁹² *International Federation for Human Rights (FIDH) v. Belgium* European Committee of Social Rights, Complaint No. 75/2011 Social Charter Decision on the Merits 18 March 2013.

²⁹³ The family as a fundamental unit of society has the right to appropriate social, legal and economic protection to ensure its full development

²⁹⁴ Citing *Autism-Europe v. France*, 13/2000 (4th November 2003) §53.

- 14.12 As a result of the landmark *Coleman v Attridge Law* (2008)²⁹⁵ ruling by the European Court of Justice in 2008, it was held that the Directive also protected the carers of disabled people ‘by association’: i.e. if they were discriminated against because they were associated with a disabled person.
- 14.13 The Act prohibits less favourable treatment based on 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.
- 14.14 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).

Associative discrimination

- 14.15 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.
- 14.16 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.
- 14.17 The Statutory Code of Practice issued by the Equality and Human Rights Commission²⁹⁶ 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

²⁹⁵ *Coleman v Attridge* ECJ C-303/06 Judgment 17 July 2008.

²⁹⁶ 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

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)

Indirect discrimination

- 14.18 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 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.
- 14.19 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 135²⁹⁷ – requires that councils record the number of carers helped following a carer's assessment expressed as a percentage of all service users. Analysis of this figure may highlight disparities in various impairment sectors – e.g. that significantly fewer carers of people with mental health difficulties get help compared to those caring for people with other impairments.
- 14.20 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.*
- 14.21 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.*
- 14.22 The potential impact of the 'indirect discrimination' provisions can be explored by considering the familiar problem many carers experience, of

²⁹⁷ Audit Commission NI 135 'Carers receiving needs assessment or review and a specific carer's service, or advice and information'.

agencies that have inflexible appointments arrangements, for example, GPs. Frequently a carer will have to make advance arrangements (for alternative care) 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). The same would be the case where – for example – hospital appointments are given with only 24 hours notice (i.e. a carer put on a 4 month waiting list, but told they will only have 24 hours notice when their slot becomes available).

- 14.23 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.

Public sector equality duties

- 14.24 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.²⁹⁸
- 14.25 *In R (Brown) v Secretary of State for Work & Pensions (2008)*²⁹⁹ 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).
- 14.26 One important aspect of the duty is the requirement that public bodies must consider the impact of their policies and practices – 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 ensure that they advance the authority’s ‘equality duties’.
- 14.27 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

²⁹⁸ 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.

²⁹⁹ [2008] EWHC 3158 (Admin) (paras 84 – 96).

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.

- 14.28 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' – i.e. 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 scheme³⁰⁰ 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'.
- 14.29 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' Strategy³⁰¹ 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.³⁰² 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 service for them, not carers.³⁰³ 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.

³⁰⁰ For example the 2010 Care Quality Commission's Equality and Human Rights scheme placed 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'.

³⁰¹ Department of Health (2008) Carers at the heart of 21st-century families and communities. Para 3.11.

³⁰² See for example Princess Royal Trust (2009) *Trust calls for Primary Care Trusts to fund respite breaks* Press Release August 6, 2009.

³⁰³ See *Carers and their Rights* (footnote 5 above) para 5.7.

15. Complaining

- 15.1 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 7.20 above). A carer will also be entitled to complain in their own right if, for example, if they are refused an assessment or a service.

Representative complaints by carers

- 15.2 Not infrequently, 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.
- 15.3 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'.

Where the disabled person agrees.

- 15.4 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 15.10 below concerning confidentiality issues). While 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.

Where the disabled person lacks mental capacity.

- 15.5 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.³⁰⁴
- 15.6 In all but the most exceptional cases a carer will self evidently be someone with a sufficient interest to bring such a complaint. 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'³⁰⁵ (see para 15.10 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,³⁰⁶ authorities should be very cautious about deciding that a carer is not suitable.
- 15.7 As the 2010 hospital discharge guidance (see para 7.19 above) states,³⁰⁷ in such cases the carer's role 'is to represent the patient's interests, and to challenge any decision that does not appear to be in the best interest of the patient'.
- 15.8 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.

Where the carer is not considered a 'representative'

- 15.9 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 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

³⁰⁴ These two criteria are specifically identified as the key criteria by the National Health Service (Complaints) Regulations 2004 SI No. 1768, reg 8.

³⁰⁵ I.e. under s4 Mental Capacity Act 2005

³⁰⁶ Because the authority could be accused of making such a finding to fend off an otherwise valid complaint

³⁰⁷ Department of Health *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care* (2010) page 19.

consideration in a way which equated to the standard of service a complaint would have received under the council's formal complaints procedure'.³⁰⁸ The NHS Ombudsman has taken a similar line – see para 15.12 below.

Confidentiality

- 15.10 In the ordinary course of events authorities will be required to accept complaints made by carers in a representative capacity. In those cases where the carer lacks the expressed '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:

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.

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 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 ...

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.

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.

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

- 15.11 A failure by a health or social services authority to undertake a 'best interests' assessment as to the disclosure of information in such cases, could amount to maladministration. The Local Ombudsman in a complaint's report³⁰⁹ 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.

³⁰⁸ Complaint No. 94/C/2959 against Nottingham City Council; 28 November 1994 and see also Complaint No 97/C/1614 against Bury MBC (1999).

³⁰⁹ Complaint no 97/C/4618 against Cheshire, 1999.

- 15.12 In similar terms the NHS Ombudsman has upheld a complaint,³¹⁰ 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 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 divulging information to the friend, or if any aspects of his complaint could be responded to without releasing confidential information.
- 15.13 Research suggests that some professionals use 'confidentiality smokescreens' as a way of withholding information from carers.³¹¹ Research also provides evidence of good practice in such cases, for instance that social and health care professionals should anticipate such problems and negotiate, in advance, agreements when the disabled person has the capacity to consent and insight into their needs³¹² or ensure that disclosure of non-sensitive material is made – with the sensitive data excluded or redacted etc.
- 15.14 The above good practice advice is reinforced by General Medical Council³¹³ 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).
- 15.15 Where the relevant person lacks sufficient mental capacity, local authorities and NHS bodies must understand the importance of involving carers and of including them in the decision making process – and a failure to have proper regard to (and understanding) of this obligation will constitute maladministration.³¹⁴ The importance of involving carers has also been emphasised in National Institute for Health and Care Excellence (NICE) guidance on dementia³¹⁵ which has as key principle (principle 4):

the imperative in dementia care to consider the needs of carers...and to consider ways of supporting and enhancing their input to the person with dementia....Health and social care staff should take account of the views of carers and relatives who describe behaviour that could be

³¹⁰ 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.

³¹¹ 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.

³¹² 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.

³¹³ *Confidentiality Guidance issued by the General Medical Council* (2009) at para 57 - 66.

³¹⁴ Joint NHS & Local Government Ombudsman Report on complaint no 11004229 against Kirklees Metropolitan Borough Council and South West Yorkshire Partnership NHS Foundation Trust 20 November 2013 para 87.

³¹⁵ National Institute for Health and Care Excellence (NICE) 'Supporting people with dementia and their carers in health and social care' (NICE 2006).

in keeping with dementia. This information...will help with diagnosis and deciding on care.

- 15.16 A detailed consideration of local authority and NHS complaints procedures lies outside the scope of this Guide.³¹⁶ In England however, there is a single approach for dealing with complaints about NHS and adult social care services. Individual authorities are able 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

- 15.17 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).³¹⁷

³¹⁶ For a detailed explanation of the procedures, see L Clements *Community Care and the Law*, (2015 Legal Action Group).

³¹⁷ In England the Local Government Ombudsman web site is at www.lgo.org.uk/; the Health Services Ombudsman is at www.ombudsman.org.uk/



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

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Carers UK is the leading campaigning, policy and information organisation run by carers, for carers. We provide information and advice to individual carers and professionals working with carers. We campaign, seeking changes from policy makers, employers and service providers, which will help to improve carers' lives. Carers UK carries out research and develops policy solutions based on carers' experiences and what they want to see changed.

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