

**Carers and Disabled Children  
Act 2000 and Carers  
(Equal Opportunities) Act 2004  
Combined Policy Guidance**



**DEPARTMENT OF HEALTH INFORMATION READER BOX**

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# Foreword

One of the most important things that this government can aim to deliver is dignity for all. No matter what their circumstances, everyone should expect that a normal life – the kind they want to live – is within their grasp.

What is also clear is the incredible contribution that carers make to enabling people to reach that goal. The range of carers' contributions varies, from a few hours a week to full-time, continuous care. However, by looking after family, friends or partners who are ill, frail or have a disability, through thick and thin, carers are perhaps our strongest ally as we work towards our agenda of dignity for life.



Some people might be surprised by quite how many people out there are making a difference. The 2001 census showed that in England and Wales there are 5.2 million carers – one in ten of the population. Over a million of these carers spend 50 hours a week or more caring – more time than most of us spend working. Every day, another six thousand people take on a caring responsibility. This is a cause for concern when research has shown that caring carries a financial cost – with the majority of carers reporting that they have become worse off as a result of caring – and a health cost – with people caring for 50 hours a week or more twice as likely as someone without caring responsibilities to be in poor health.

Many of these carers are parents of the 770,000<sup>1</sup> disabled children in the UK. The Prime Minister's Strategy Unit's report *Improving the Life Chances of Disabled People* is the government's long-term strategy to improve outcomes for disabled adults and children. In addition, *Choice for parents, the best start for children: a ten year strategy for childcare* will offer parents more choice in balancing work and family life with a strong focus on parent carers of disabled children.

But of course not all carers are adults. Although estimates vary, the 2001 Census recorded a total of almost 150,000 young carers, of whom the most numerous group were 12-14 year olds who provided 1 to 19 hours of care each week. It is vitally important that caring does not have a negative impact on their development, and we want to ensure that young carers get the best chance in life through educational opportunities, health care and social care.

1 Family Resources Survey G.B. (2002-03), DWP

So if carers are to be able to continue their vital role of helping to deliver dignity, we need to ensure that they are well supported. The National Carers Strategy, published in 1999, set out the government's plans to support carers in a practical way, through the provision of information, helping carers to stay in employment, and by helping carers to care for themselves.

In 2000, the Carers and Disabled Children Act built on that strategy by giving carers the right to an assessment, even if the person they care for had refused one. This gave local councils the opportunity to provide carers with services that meet their own assessed needs – a very important step for carers. The Act also meant that carers could be given a direct payment for the first time, giving them flexibility and choice in meeting their own needs.

Now, through the Carers (Equal Opportunities) Act 2004, carers have access to more support than ever. Information is key to enabling carers to make choices about their personal life, and the new Act requires local authorities to inform carers about their right to an assessment of their needs.

Another key element of the new legislation is a recognition that carers should be able to live as full a life as possible. Carers make up a large proportion of the workforce, and it is vital that they are supported by employers and feel that their skills and their contribution are valued. Enabling carers to work not only increases choice and independence, but is in the best interests of society as a whole, and the government is taking a range of measures to help carers stay in – or get back into – employment. The Department for Trade and Industry for example has produced guidance on *Time off for Dependents*, setting out the rights of employees to take a reasonable amount of time off work to deal with certain unexpected emergencies and to make any necessary longer term arrangements.

I feel very strongly that we should not just pay lip service to carers' contribution to society, but make every effort to ensure that carers can access the same opportunities that are available to those without caring responsibilities. From now on, all assessments will have to recognise not only whether a carer wants to work, but also whether they want to take part in education, training or leisure activities. Being able to enjoy the pursuits that should be open to everyone is one way in which carers can have some control and choice in their own lives. By implementing this legislation we can afford carers the same dignity that they help to deliver to those they care for.

Supporting carers in their caring role is not just the job of the person carrying out the carer's assessment, or even the local authority. Other organisations – like NHS trusts or housing authorities – also have a duty to help by giving proper consideration to any request for help with the provision of services following a carer's assessment. Many organisations have been following this best practice for some time, but the good news for carers is that the duty has now been set down in legislation.

We as a government have demonstrated our commitment to carers through the carers' grant, which this year increased by £60 million to £185 million, with 20 per cent of the grant allocated to children's services as in previous years. Carers tell us that the most effective way of supporting them is providing a means for them to take a break, and the carers' grant gives local authorities a means of doing this in a flexible and innovative way.

Research has shown that most people – around one in three – will become a carer at some point in their lives. The ageing population also means that there is greater chance that we will have to look after a frail relative or friend as they get older, and many of us are already doing so. Any of us could become a carer, either suddenly or over time, and none of us can take carers for granted. The Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 are a vital part of our commitment to value the contribution that carers make to our communities and help those who need support to maintain their dignity for life.

A handwritten signature in black ink, appearing to read 'Liam Byrne', with a long horizontal line extending to the right.

**Liam Byrne**  
**Parliamentary Under Secretary of State for Care Services**  
**August 2005**

# Executive Summary

This combined policy guidance updates the *Carers and people with parental responsibility for disabled children policy guidance* issued in March 2001, which accompanied the Carers and Disabled Children Act 2000.

New guidance is required because the Carers (Equal Opportunities) Act 2004 makes three principal changes to previous carers legislation which will need to be taken into consideration by local authorities. These changes are summarised below:

## *Duty to inform*

The 2004 Act develops previous legislation by requiring local authorities to inform carers that they may be entitled to an assessment of their needs. Local authorities may need to develop an information strategy to ensure that carers are being told of their rights and that the large number of ‘hidden’ carers (those not known to the local authority) are being reached.

## *Carer's assessment*

As a result of amendments made by the 2004 Act, carers’ assessments must now include a consideration of whether the carer works or wishes to work, and whether they participate or wish to participate in any education, training or leisure activity. This recognises that carers should be able to take up opportunities that those without caring responsibilities take for granted.

## *Cooperation between authorities*

The 2004 Act requires that when a local authority requests another public authority – such as an education, housing or health body – for assistance in planning services for a carer, that authority must give due consideration to the request. This helps local authorities to ensure that they are working in partnership with other bodies to provide a seamless service for carers and the people they care for.

The new guidance therefore sets out the issues for local authorities in carrying out their functions under both the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004.

# Part I – Background

## Purpose

1. The aim of this policy guidance (which is issued under section 7(1) of the Local Authority Social Services Act 1970) is to set out the Government's view of the issues for local authorities in carrying out their functions under the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 as they affect:
  - carers who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over;
  - people with parental responsibility for a disabled child who provide or intend to provide a substantial amount of care on a regular basis for the child.
2. In dealing with the needs of children who are carers (including those aged 16 and 17) the *Framework for the Assessment of Children in Need and their Families* remains the main source of guidance for local councils.

## Background to Carers Legislation

### The Carers (Recognition and Services) Act 1995

3. The first piece of legislation for carers was the Carers (Recognition and Services) Act 1995 ("the 1995 Act"). It was seen as a major step forward for carers, giving them important new rights and a clear legal status. Under the Act, individuals who provide or intend to provide a substantial amount of care on a regular basis are entitled to request (at the time the person they care for is being assessed for community care services) an assessment of their ability to care and to continue caring. Local authorities are required to take into account the results of that assessment in making decisions about the type and level of community care services to be provided to the cared for person. The assessment under the 1995 Act is of the carer's ability to provide care and of his or her ability to sustain the care that he or she has been providing. The 1995 Act applies to carers of all ages.

## **The Carers and Disabled Children Act 2000**

4. The Carers and Disabled Children Act 2000 (“the 2000 Act”) made four principal changes to the law, with the objective of enabling local authorities to offer new support to carers to help them to maintain their own health and well being. The 2000 Act applies to carers aged 16 and over and people with parental responsibility for disabled children.
5. Under the 2000 Act local authorities have the power to supply certain services (those services which help the carer to care) direct to carers following assessment. It gives carers the right to an assessment independent of the community care assessment for the cared for person. This enables a local authority to carry out an assessment in circumstances where the cared for person has refused an assessment for, or the provision of, community care services.
6. The 2000 Act empowered local authorities to make direct payments to carers (including 16 and 17 year old carers) for the services that meet their own assessed needs. Since the Carers and Disabled Children Act 2000, the legislative framework relating to direct payments for carers has been updated through Section 57 of the Health and Social Care Act 2001.
7. In addition, the 2000 Act provides for local authority social services departments to run short term break voucher schemes. Voucher schemes are designed to offer flexibility in the timing of carers’ breaks and choice in the way services are delivered to cared for people while their usual carer is taking a break. And finally, the 2000 Act amends the Health and Social Services and Social Security Adjudications Act 1983 to give local authorities a power to charge carers for the services they receive.

## **The Carers (Equal Opportunities) Act 2004**

8. The Carers (Equal Opportunities) Act 2004 (“the 2004 Act”) seeks, through section 1, to give carers more choice and better opportunities to lead a more fulfilling life by ensuring that carers receive information about their rights to an assessment under the 2000 Act. Section 2 ensures that those assessments now consider the carer’s wishes in relation to leisure, education, training and work activities. Section 3 provides for co-operation between local authorities and other public authorities, including housing, education and health, in relation to the planning and provision of services that may help support the carer in their caring role.

## The Acts in relation to Young Carers

9. By amending section 1 of the Carers (Recognition and Services) Act 1995, the new sections 1 and 2 in the Carers (Equal Opportunities) Act 2004 require councils to inform carers of their right to assessment and consider whether a carer works, wishes to work or wishes to undertake education, training or leisure activities. As these sections amend the 1995 Act, which applies to carers of all ages, the sections also apply to carers of all ages including those aged under 16. Section 3 (6) of the 2004 Act nevertheless makes it clear that the duty of co-operation between authorities required by that Section does not apply where the equivalent duty under section 27 of the Children Act 1989 already applies.
10. Children (anyone aged under 18) who are carers should be routinely assessed under the Children Act 1989. As a matter of law they could be assessed under the 1995 Act but that would not be expected, nor would it be in line with the Children Act 1989 guidance. Nevertheless, whichever of these Acts they were assessed under, the new obligation to consider a young carer's wish to work or undertake education, training or leisure would still apply – for example if a 15 year old wanted to take up a paper round. The rights of young carers to the same life chances as their peers – including appropriate work, leisure, education and training – are also addressed through the *Framework for the Assessment of Children in Need and their Families*.
11. In dealing with the needs of children (including those aged 16 and 17) the *Framework for the Assessment of Children in Need and their Families* therefore remains the main source of guidance for local authorities. Where children – including those aged 16 or 17 – are involved, either as the recipients of care or as carers themselves, the assessment of the child's needs, and the capacity of their parent(s) to respond appropriately to those needs within their family context, should follow this framework. The *Framework for the Assessment of Children in Need and their Families* provides, however, that with any child or family referral, social services should check whether a person with parenting responsibility has needs independent of their child's needs, which may call for the provision of adult community care services. If so, those needs should be further assessed in accordance with the Department of Health guidance, *Fair Access to Care Services* (FACS).
12. The Assessment Framework provides that local authorities ought to consider the individual developmental needs of the child, the parent's capacities, and environmental factors to form a holistic child-centred picture of the needs of the child and their family. The assessment of the parent's or carer's needs should be a separately identified but integral part of this assessment. Providing services which meet the needs of parents is often the most effective means of promoting the welfare of disabled children and

other children in need. Enabling disabled parents to fulfil their parenting roles will often bring benefits to their children as well, by improving the overall well-being of the family.

13. The Assessment Framework includes specific and detailed guidance in relation to young carers (see paragraphs 3.61 to 3.63 in particular) and families with disabled children (see in particular chapter 3 of the practice guidance.)
14. The provision of specific services and support groups for young carers may provide a valuable resource to help this particularly vulnerable group of carers. Adults' and Children's services within local authorities may wish to work together to develop services and support that meet the specific needs of young carers as children in need. They may also wish to consider what role the voluntary sector and/or other statutory agencies, for example *Connexions*, could play to support these carers.

## Policy Context

15. Carers play a vital role in our communities, including enabling people that wish to stay in their own homes to do so and to remain independent. In recognition of this role, the Government's aim is to support people who choose to care and to help them maintain their own health and well-being by ensuring that local authorities take into account carers' lives outside the caring role. The Government recognises that being a carer should not mean that a person is unable to take up opportunities that those without caring responsibilities take for granted.
16. In 1999 the Government formally acknowledged the contribution and concerns of carers through a cross-government National Carers Strategy *Caring about Carers*. The strategy provides best practice in supporting carers and was developed with carers and organisations that represent them. It identified key areas in supporting sustainable caring relationships including information, access to breaks and services and carer and voluntary sector involvement in planning and providing services. Subsequent carers legislation (detailed above) has now enshrined in law some of the best practice highlighted in that strategy. This strategy also highlighted the specific needs of young carers and provides examples of best practice in providing help for young carers at a local level.
17. The recently published Green Paper *Independence, Well-being and Choice – Our vision for the future of social care for adults in England* sets out the Government's proposals for the future direction of social care for all adults in England and emphasises the importance of carers and the need to ensure they are integral to this vision.

18. Providing the right level of support for carers and enabling them to make choices about their personal life is key to supporting carers in undertaking their vital role. Assessments and services for carers should be person-centred, seamless and pro-active. They should help support the carer to maintain their own independence and allow them to enjoy a good quality of life. Carers should be treated with dignity and respect and supported to overcome the barriers they face to partaking in the normal parts of everyday life. In doing so, assessments and services should be tailored to the religious, cultural and ethnic needs of the individual. They should focus on positive outcomes and well-being, listening to what the carer really wants and being more flexible and imaginative in identifying ways in which those needs may be met. For example, a carer may be best supported through being given help with routine domestic chores rather than through additional community care services to the person they care for.
  
19. Under the 2000 Act, eligible carers have the right to request an assessment of their own need for services. However, in order to do this carers need to know they have this right. Obtaining information about their rights is the first step for a carer towards getting support at the right time, if they choose to do so. Better information can enable carers to retain greater control over their lives and, where appropriate, take more responsibility for accessing the help and assistance they need. Carers rate information as one of their top priorities and the Government wants to see increased take-up of carers' assessments. Many carers do not recognise themselves as carers and even when they do, accessing the right information to assist them in their caring role can be fraught with difficulties. Many carers choose to have no contact with social services and see the voluntary sector as the best way to get what they need.
  
20. The 2004 Act is an important step in helping to ensure that carers get information about their rights at an appropriate time. As the Act places a duty on local authorities to inform carers of their rights to an assessment, all local authorities will need to consider how they are meeting this duty. This may include exploring how they can provide better information which is easy to understand and is available in minority languages and a variety of formats including easy to read, Braille or audio tapes. Other ways of providing information and advice that are sensitive to language and cultural needs may also need to be developed.
  
21. Individuals may provide care for a range of very personal reasons, from family ties to the absence of adequate substitute care. Some carers choose to care full time and are happy to do so, others report that they feel they have little choice. A large proportion of carers combine work with their caring role. This often comes at a price for the carer in terms of their own health and well-being as well as self-esteem and prospects for employment. Carers represent a significant part of the skilled workforce. It is important that carers with experience are able to keep their jobs or are able to return

to work after their caring role ceases or reduces. Those who wish to care full time should be able to do so with the support they need and those who wish to should be able to combine normal everyday activities with caring.

- 22.** The 2004 Act also means that, for the first time, local authorities must, when carrying out carers' assessments, consider how service provision will impact on the carer's life in relation to their opportunities to work or undertake education/training or leisure activities. Many carers are significantly worse off financially due to the impact of their caring role and others have to give up employment altogether due to their caring responsibilities. Some carers would like access to training and support in their caring role or may feel that their own personal development and general mental and physical well-being would be enhanced by undertaking leisure activities and/or training or education. Local authorities now have to consider these issues and the carer's wishes when planning the care package for the person they care for, and where possible should look to using flexible carers' services and/or direct payments to help put in place a package of support designed to meet the holistic needs of the carer to support them in their caring role.
- 23.** Research shows that six out of ten carers say that being able to take a break from caring is the most effective way to support them and enable them to continue caring. For those who are unable to take a break or do not wish to do so, however, provision of services direct to the carer or the person they care for should be flexible and responsive, tailored as far as practicable to individual needs and circumstances. Offering choice in how services and support are provided can lead to imaginative and cost-effective packages, which achieve the desired outcomes and reflect the needs of those needing support. The Government's aim in promoting direct payments is to increase individuals' independence and choice by giving them control over the way the services they are assessed as needing are delivered. Direct payments can give carers and the people they care for flexibility to look beyond "off the peg" service solutions for certain housing, employment, education and leisure activities as well as for personal assistance to meet their assessed needs. Direct payments provide a valuable tool to help implement the requirements of the new Act.
- 24.** Supporting carers is a crosscutting issue and the key to excellence must therefore be effective partnership working between public authorities as well as with local voluntary and independent organisations. The 2004 Act provides a formal basis for co-operation between public authorities to deliver a more coherent service for carers. At a strategic level, it provides local authorities with a lever to influence the priorities of their colleagues in health and other authorities in relation to the planning and provision of services for both the carer and the person they care for. It also provides for engagement at an individual level and consideration of an individual carer's

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

25. Helping carers is one of the best ways of helping the people they care for. In doing so, however, it should be remembered that there will be times when the caring relationship becomes unsustainable. Where this is the case, for whatever reason, the carer may have feelings of guilt and of having failed in their caring role. It is important in these cases that the carer's feelings and emotions are taken into account and handled with sensitivity. Whilst it is the Government's policy to provide carers with the support they need in their caring role, people should not be left with no option but to care particularly where the caring role puts that person at risk.

# Part II – Carers who Provide or Intend to Provide a Substantial Amount of Care on a Regular Basis for Another Individual Aged 18 or Over

## Scope of the Acts

### Right of carers to assessment

26. Under section 1 of the 2000 Act, carers aged 16 or over are eligible for an assessment of their ability to provide and continue to provide care where:
- the carer does not provide or intend to provide the care under a contract or as a volunteer for a voluntary organisation;
  - they provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over;
  - the local authority is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services; and
  - the carer asks the local authority to conduct an assessment
27. This right exists even where the cared for person has refused an assessment by the local authority's social services department, or has refused the delivery of community care services following assessment.

### Carer's assessment

28. As a result of amendments made by the 2004 Act, a carer's assessment under the 2000 Act must now include a consideration of whether the carer works or wishes to work and whether or not the carer is undertaking, or wishes to undertake, any education, training or leisure activity. This means that local authorities have a duty to ask carers about these activities and take their wishes into account when planning the care package. Good practice would include a discussion with the carer about possible alternative care services to help enable them to take up opportunities to participate in these activities, as well as signposting carers to information and support services, for example Job Centre Plus or local voluntary organisations who may be able to offer help and support. Voluntary work placements may also be helpful in supporting carers to build skills and confidence to help them into employment. Local authorities

may also wish to consider that some carers, for example those who care for people with learning disabilities, may have particular needs because of the length of time that they have been caring or are expected to continue to care.

29. Although it is recognised good practice, in some local authorities carers' assessments undertaken prior to 1 April 2005 may not have included a consideration of their wishes in relation to work, training and leisure. Where this is the case, and where the carer so wishes, local authorities may wish to reassess these carers under the provisions of the new Act. Reassessment is also appropriate where there is a significant change in the level or nature of the caring role or a change in personal circumstances that has a significant impact on the carer's ability and willingness to care.

### **Duty to inform**

30. By virtue of the 2004 Act, where it appears to a local authority that it would be required to carry out a carer's assessment under the 2000 Act on being asked to do so by a carer, the authority must ensure that the carer is informed that he or she may be entitled to such an assessment. This does not apply where the carer has already been informed that he or she may be entitled to carer's assessment or where the authority has previously carried out such an assessment on his or her behalf in relation to the cared for person.
31. Local authorities may consider developing an information strategy to help ensure that carers are getting information about their rights in a consistent way. This could include routinely informing the carer of their rights, at the time of the community care assessment for the person being cared for, by word of mouth, by being given a leaflet etc. Good practice would include explaining what an assessment involves and how it is intended to identify help and support rather than being a test of how well a person is caring.
32. There may be instances where neither the cared-for person nor the carer is in contact with the local authority, for example in some longstanding caring relationships between older carers of people with learning disabilities and also some carers from minority ethnic communities. There are also many people who do not recognise themselves as a carer and see it more as their 'duty'. To reach these and other hidden carers, local authorities may wish to consider working with local statutory and voluntary sector partners to develop strategies for better communication with 'hidden' carers about their right to request an assessment. This could include Carer Awareness sessions being incorporated into training for health and social care staff; campaigns to help carers recognise themselves as carers; posters and leaflets in GPs' surgeries; and building links with local communities and faith groups. The Carers and Disabled Children Act 2000 practice guidance sets out examples and good practice in helping to ensure that carers

are aware of their rights and in reaching out to hidden carers. Following a carer's assessment, the local authority has a duty to take into account the results of the assessment when deciding what services to provide to the cared for person.

### Co-operation between authorities

33. Partnership working is vital to ensuring that carers receive cohesive and seamless services. As good practice authorities may wish to work with their local partners in health, other public authorities and the voluntary and independent sectors to develop a multi-agency carers strategy. These strategies, where developed in partnership with and signed up to by partners, may provide a valuable tool to facilitate partnership working to help ensure that the spectrum of carers' needs are met. They could also help ensure that agreed protocols are in place for support from partner organisations in providing support to carers. This sort of process may also help to embed carers' needs in other local strategies, for example, welfare to work, joint investment plans, hospital discharge plans and life-long learning strategies. The 2004 Act aims to foster joint working to deliver comprehensive services for carers and will enable social services departments to be better able to call on other authorities to assist in supporting carers and will provide a formal basis for co-operation between authorities to deliver a more coherent service for carers. These authorities are:
- other local authorities,
  - any local education authority,
  - any local housing authority,
  - and certain National Health Service bodies, including any Primary Care Trust, any NHS Trust or NHS Foundation Trust, and any Local Health Board
34. The new performance framework for the NHS and Social Care (*National Standards, Local Action*, July 04) sets out a number of core and developmental standards for the NHS in the domains of *patient focus* and *accessible and responsive care* which include elements of supporting carers. In addition, the *public health* domain requires NHS organisations to cooperate with each other, with local authorities and with other organisations to promote, protect and improve the health of their community and narrow health inequalities.
35. Where a local authority requests one of the public authorities listed above to assist it in the planning and provision of services for carers or cared for people, the authority must give due consideration to the request. This will ensure, for example, that a local authority is better placed to seek information from, or the participation of, the NHS when deciding how to deliver carers' services that are linked to local NHS services. For example, local authorities will be able to ask an NHS trust to provide access for a carer

to an NHS counselling service. In addition, where a local authority is assessing or has assessed the carer's need for services under the 2000 Act and believes a carer's ability to care may be enhanced by the provision of services to the cared for person from another authority, that authority must give due consideration to the request. For example, access to patient transport services, the provision of housing adaptations or priority housing relocation, or perhaps leisure services working to support a disabled person whilst the carer does other things or joins them in their leisure activity. The cooperation provisions aim to give authorities levers at a strategic level to influence the priorities of their colleagues in health and social care as well as levers for authorities to engage at an individual level with their partners to support individual carers.

### **Due consideration**

36. Due consideration means that a public authority which is asked for assistance by a local authority in accordance with the 2004 Act must give appropriate thought to the actual request that is made of them. What this means will vary from case to case, but the authority to whom the request is made cannot fail to consider it, dismiss it arbitrarily, or have a blanket ban on considering certain types of requests. This means, for example, an NHS organisation could not refuse to consider any request made to them in relation to the provision of lifting and handling support for carers. The 2004 Act does not, however, authorise or require the public authorities to act beyond their powers in order to meet a request, nor does it impose an obligation on the public authority that receives the request to comply with it. Although that authority cannot simply ignore the request, whether or not it is complied with is a question for local judgement. Local authorities may wish to consider working with public authorities to develop standard protocols, for example agreeing what would be a reasonable timescale for dealing with a request. In demonstrating that due consideration has been given, it would be reasonable to expect public authorities to document the decision taken in relation to requests, along with the reasons for that decision.

### **Where the cared for person refuses assessment or services**

37. For a carer to be entitled to an assessment under the Carers and Disabled Children Act 2000, the local authority must be satisfied that it may provide or arrange community care services for the cared-for person. In some circumstances, the cared-for person may have recently been assessed under community care legislation but has refused services following assessment. If a satisfactory level of information about the carer and the cared for person is already available to the local authority and the cared for person's views on contact with social services are known, the local authority may wish to proceed with an assessment of that carer's needs without further enquiry.

38. If the cared for person has not undergone a recent community care assessment, the local authority should develop a protocol to ensure they are able to make reasoned judgements about whether the carer is entitled to an assessment. See the conditions set out in paragraph 26 above. In the first instance this should usually mean approaching the cared for person to ascertain if they are willing to be assessed, although local authorities may first wish to consider whether this could be inappropriate or even harmful to the carer.
39. Where the cared for person is unwilling to be assessed, local authorities should use the Contact Assessment on either the cared for person or the carer themselves to make a reasoned judgement about the need to conduct a carer's assessment. A contact assessment is the first point of contact between a carer or cared for person and social services, at which basic personal information is collected, the nature of the presenting problem is established, and the potential pressure of wider health and social care needs is explored.

#### **Links with Carers (Recognition and Services) Act 1995**

40. Information gathered under an assessment under the Carers (Recognition and Services) Act 1995 can be taken account of in assessments conducted under the Carers and Disabled Children Act 2000 and vice-versa.

#### **Disabled Persons (Services, Consultation and Representation) Act 1986**

41. The impact of caring on the carer should still be taken into account and recorded as part of the cared for person's assessment, even if it is not deemed to amount to a 'substantial and regular' caring role. Where a carer is providing a substantial amount of care on a regular basis, Section 8 of the Disabled Persons (Services, Consultation and Representation) Act 1986 requires the local authority to consider the carer's ability to continue to provide care when deciding what services to provide to the disabled person.
42. Full involvement of individuals and their carers in both assessment and care planning has long been recognised as good practice. The *Community Care Assessment Directions 2004* place existing good practice and guidance on conducting care assessments and care planning into a legal framework. Further information on Community Care Assessments is available through LAC(2004)24.

#### **A carer centred approach to assessment**

43. Front line staff should adopt a carer centred approach to assessment. This may be achieved by listening to carers and looking to achieve outcomes which, while helping the carer to care, take account of the carer's life beyond their caring. In looking at the

carer's willingness and ability to care, consideration should be given to the carer's attitude and mental capabilities and not just their physical ability. Some people, for example, could provide care but may feel subject to a moral obligation to do so, or may feel defeated, trapped or depressed. The assessment of the person's willingness and ability to care must also now take into consideration, for example, whether the carer works or wishes to work or undertake education, training or any leisure activity.

44. Local authorities will need to review, and in some cases amend, their assessment procedures to ensure that they have incorporated issues of work, life-long learning, training and leisure. They will also need to consider how they ensure that all staff involved in carrying out carers' assessments are aware of the requirements of the 2004 Act. This could include holding awareness raising sessions, amending existing training programmes, articles in staff newsletters and so on. Fuller guidance on carers' assessments can be found in the existing Practice Guidance and the *Practitioners Guide to a Carer's Assessment* which accompanied the 2000 Act. Fuller guidance specific to the 2004 Act will be contained in the new Carers Practice Guidance being developed by the Social Care Institute for Excellence (SCIE) to be available autumn 2005. Local authorities will also need to keep in view other related policy documents. *The Mental Health National Service Framework* states that carers of people with severe mental illness should have an assessment of their caring, physical and mental health needs at least annually, and have their own written care plan which is implemented in discussion with them. In the *National Service Framework for Older People*, the needs of carers are considered as an integral part of the way services are provided to older people. In particular, Standard Two (Person Centred Care) requires managers and professionals to involve and support carers whenever necessary. The *National Service Framework for Long Term Conditions* (QR 10) and *Valuing People* (chapter 5) should also be considered.

### **Carers' assessments carried out by other organisations**

45. There may be instances where a local authority feels that another organisation may be best placed to provide carers' assessments for some people. In these circumstances local authorities can ask other organisations (for example in the voluntary sector) to become involved in assessments, but as they have a statutory duty of assessment they will want to ensure that all assessments that include a social care element are carried out in the appropriate way. A local authority may contract with another body to carry out part of the assessment process on its behalf, for example interviewing the carer, researching possible assistance, preparing a report and even making a recommendation. However, as an assessment is a statutory function of the local authority it will have to make the final decision about whether or not to provide services itself. It is not enough for the local authority to simply check on a complete or partial basis the outcomes of another organisation's assessments.

### **Substantial and regular**

46. Prior to undertaking an assessment of the carer's needs, the local authority will begin by satisfying themselves that the cared for person is someone for whom it may provide or arrange for the provision of community care services. See paragraphs 26 to 39 above. It is possible that there may be more than one carer providing substantial and regular care in each household who is entitled to an assessment under the provisions of the 2000 Act.
47. Once the local authority is satisfied as to the status of the cared for person, it is a matter of professional practice and an essential component of the assessment to identify the impact of the caring role on the carer in light of the carer's age, general health, employment status, interests and other commitments.
48. There is no definition in the 2000 Act of "substantial and regular care". The process of assessing the impact of the caring role on the carer, and thus whether the care provided is regular and substantial, is based on a consideration of two dimensions:
- key factors relevant to sustaining the chosen caring role,
  - extent of the risk to the sustainability of that role.
49. Any such judgement should recognise that it is not only the time spent caring that has an impact on carers. For some, such as those caring for disabled children or adults with learning disabilities, the caring role can have the additional impact of being a life long commitment. Others, for example people caring for those with mental health problems or some neurological conditions, may have responsibilities that are not necessarily based on physical tasks and the caring role may be sporadic or preventative in nature. The carer may not be physically or practically caring at all times, but may still be anxious or stressed waiting for, or trying to prevent, the next crisis. In addition, caring responsibilities may conflict with other family responsibilities such as parenting or holding down a job. Any assessment of the carer's need for support has to look at the impact of the whole caring situation. Further guidance to help local authorities set their own criteria for what constitutes substantial and regular care may be found in the *Carers and Disabled Children Act 2000 Practice Guidance*.

### **Promoting and safeguarding the welfare of carers age 16 or 17**

50. The 2000 Act and the 2004 Act will only rarely be used by authorities looking at the needs of 16 and 17 year old carers. In most circumstances, the local authority should ensure that the cared for person is receiving sufficient services so that a young person aged 16 or 17 is not undertaking a regular and substantial load of caring responsibilities. As with all children living with disabled, vulnerable or frail older

people, the local authority should ensure that such young people's futures are not adversely affected by caring responsibilities that may undermine their own need to participate fully in education, training, leisure or work. There are, however, a small number of situations where it is in the best interests of the 16 or 17 year old that he or she is supported to undertake a substantial caring role for a period, for example if a parent is terminally ill. In the rare circumstances where local authorities are satisfied that the child's welfare can be promoted and safeguarded as they take on a substantial caring role, it could decide that it would be more helpful for a young person to receive services under the provisions of the 2000 Act. Any assessment of such 16 and 17 year old carers should still be child centred and follow the guidance set out in the *Framework for the Assessment of Children in Need and their Families*, paying particular attention to paragraphs 3.61 to 3.63.

### **Assessments and services for both carer and cared for person**

51. Following assessment, the best outcomes for both cared for people and carers are still likely to result from the provision of good quality community care services for the cared for person. In addition, the local authority must consider the information gathered and decide whether to provide services to the carer.
52. Services to carers are not defined as such in the 2000 Act. The local authority may provide any services they see fit to provide and which in their view will help the person care. These services may take any form, for example, a gardening service or assistance around the house for a carer who devotes most of his or her time to providing intimate care to the person cared for. Practitioners carrying out carer assessments are encouraged to consider flexible and innovative use of services which would help minimise the impact of the caring role on the carer's own life.
53. Under the Carers (Recognition and Services) Act 1995, the assessment of a carer's ability to care may inform what services are provided to the cared for person. This means that as a result of a carer's assessment, the local authority may decide that a carer would be best supported by providing community care services to the cared for person. This means that the local authority may provide more services, different services, or deliver the same services differently. The local authority's decision to provide services is to be made without regard to the means of the carer or of the person cared for, but only on the basis of the best way of meeting the assessed needs within the caring relationship. The local authority will need to consult with both community care and carers' service users on the timing and nature of any services to be provided.

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

54. Following assessment, services provided to a person with a carer will usually be provided as community care services just as they are provided for people without carers. In some circumstances local authorities may provide a carer's service that takes the form of a service delivered to the person cared for, for example because the cared for person has refused an assessment. This flexibility is limited to services that can be provided to the cared for person through community care legislation and they may not, except in prescribed circumstances, include anything of an intimate nature. Importantly, none of this may happen unless both the carer and the cared for person agree that the service is to be delivered in this way. See also paragraphs 56 to 60 below.

### **'Services of an intimate nature' and 'prescribed circumstances'**

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

### **Services of an intimate nature**

56. Regulations define which services are, or are not, of an intimate nature.<sup>2</sup> Intimate services include such things as:
- lifting, washing, feeding, dressing, bathing, toileting, administering medicines or otherwise having physical contact with the person cared for; or
  - assistance in connection with washing, feeding, dressing, bathing, administering medicines or using the toilet; or
  - supervising the cared for person whilst they are dressing, bathing or using the toilet.
57. The purpose of defining services of an intimate nature in regulations is to prevent any services being delivered to unwilling disabled or frail older people. Therefore local authorities will also want to ensure that the circumstances of the cared for person, for example gender, cultural or religious beliefs, mental health needs, age, family life and way of living, are taken into account and that any service they are considering providing is not inappropriate. In some circumstances, for example, being asked a personal question, discussing someone's psychological concerns or their relationships with others, or generally being communicated with by someone unfamiliar may be regarded as embarrassing or intrusive.

2 See *Carers (Services) and Direct Payments (Amendment) (England) Regulations 2001*

## Prescribed circumstances

58. Regulations set out prescribed circumstances in which the delivery of intimate services as set out above could be delivered to cared for people. This would only occur where a cared for person had refused an assessment or the delivery of services following assessment, but nevertheless had later agreed to a non-intimate service being delivered to them as a carer's service. The Regulations are flexible in order to ensure that cared for people get help with intimate tasks if they change their mind while a carer's service is being delivered to them, or that appropriate help is provided in emergency situations.
59. Regulations prescribe such circumstances as being where a service is being delivered to the cared for person, and
- a) during the delivery of that service the cared for person asks the person delivering the service to provide a service of an intimate nature; or
  - b) the cared for person is in a situation in which he is likely to suffer serious personal harm unless a service of an intimate nature is provided to him and
    - (i) the cared for person is unable to consent to the provision of that service, or
    - (ii) the person providing the service reasonably believes it is necessary to provide that service because of the likelihood of imminent serious personal harm to the cared for person.
60. When such circumstances arise and the cared for person needs assistance other than as agreed as part of the service contract, the service provider should respond as appropriate. The local authority, on being informed by the service provider that an intimate service had been requested by and delivered to the cared for person, should treat this as a change of circumstances. The cared for person should then be approached at the earliest opportunity and asked if they are now willing to be assessed and/or receive services in their own right under community care legislation.

## Charging

61. Local authorities are able to charge carers for the carers' services they provide. This is by means of an amendment to Section 17 of the Health and Social Services and Social Security Adjudications Act 1983 to add a reference to the 2000 Act. The local authority decides whether or not to charge for a carer's service delivered under the provisions of the 2000 Act. *Fairer Charging Policies for Home Care and other Non-residential Social Services* and related practice guidance issued in August 2002 and September 2003 provide guidance on this.

- 62.** Carers cannot be charged for community care services provided to the people they care for (including the community care services provided to enable carers to take a break from caring) unless those services are provided as the result of a carer's assessment under the 2000 Act. Cared for people cannot be charged for the carers' services provided to their carers, including services provided as carers' services following a carer's assessment but delivered to cared for people as set out in paragraphs 54, 56 and 57 above. Any local policy on charging for non-residential services should be consistent between carers and cared for people. If both parties are being assessed for a charge for their respective services (for example if they are spouses or partners), the local authority should take care to do this in a reasonable way. There will be circumstances where a carer has been assessed for a carer's service that is delivered to the person they care for. In these circumstances the carer may be liable to pay any charge.
- 63.** Local authorities should not choose the route of service provision (that is, whether to provide services following either a carer's assessment or an assessment of the cared for person) according to whether or not either party will be liable for charging.
- 64.** Where services are provided to 16 and 17 year old carers, authorities may recover costs from the young person provided that it is reasonable to do so. Young people in receipt of certain social security benefits may not be charged. This is in line with the charging provisions for services for 16 and 17 year olds under the Children Act 1989.

## Direct payments

- 65.** The *Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003* place a duty on local authorities, in certain circumstances, to make direct payments to enable people to obtain for themselves the services that they are assessed as needing. Direct payments allow carers to purchase the services they are assessed as needing *as carers* to support them in their caring role and that may help to maintain their own health and wellbeing. However, other than those with parental responsibility caring for children, carers are not currently entitled to a direct payment to purchase services to meet the assessed needs of the person they care for. Direct payments offer carers the opportunity to be innovative and flexible in how they arrange the delivery of services to them to meet their assessed needs. Examples might include driving lessons, moving and handling classes, a mobile phone, taxis to work to maximise the carer's time, or a short holiday for the carer to enable them to have time to themselves. Direct payments could also be particularly valuable to help carers from minority ethnic communities who may not find the local authorities' support suitable and would prefer support from within their own community, or they may for example help families be more flexible in supporting people with mental illness.

66. *Direct Payments Guidance – Community Care, Services for Carers and Children’s Services (Direct Payments) Guidance England 2003* remains the primary source of guidance around the use of direct payments both for the carer and the cared for person. This document provides case study examples to demonstrate appropriate use of direct payments, for example where it may be appropriate to consider direct payments for 16 and 17 year old carers. It also provides overarching guidance on matters relating to the 2003 Direct Payment Regulations including guidance on developing, using and monitoring direct payments locally, advice relating to employment and the responsibilities of local authorities to provide appropriate information and support to help both carers and cared for people manage the direct payment.

### Short Term Break Voucher Schemes

67. The 2000 Act provides local authority social services departments with the option to run short term break voucher schemes. Short term break vouchers enable cared for people to make arrangements for the additional support they need when their carer needs a break. They offer more flexibility and choice than services provided directly by the local authority, but in a simpler way than is currently available via direct payments. For example, a cared for person may not wish to enter residential care while their usual carer is taking a break. The voucher system enables them to seek out a provider of support that will enable them to continue living at home.
68. The *Carers and Disabled Children (Vouchers) (England) Regulations 2003* provide for the value of a voucher to be expressed in terms of either money or the delivery of a service for a period of time. Time value vouchers *must* specify the service that is to be provided in order to allow the carer to take a break, although the vouchers are redeemable either against one provider or a group of providers offering a similar service. Money vouchers *do not* specify the service provider when the voucher is redeemed. Both types of voucher allow flexibility about when to arrange for the service to be delivered.
69. Further guidance on short term break vouchers is available in *Carers and Disabled Children’s Act 2000 – Vouchers for short-term breaks – Policy and Practice Guidance*, issued by the Department of Health.

## Complaints procedure

70. Local authorities are required to operate a procedure for considering any representations (including any complaints) which are made to them about the discharge of their social services functions or any failure to discharge those functions. It is important to ensure that people are aware of the complaints procedure, particularly when they are informed of a decision they may not welcome. People, including both carers and cared for people, may make complaints about any action, decision or apparent failing of the local authority, but not about services which they have secured from independent providers (including people they employ directly) using direct payments. In those circumstances, people will need to address any complaints about such services to the service provider.

# Part III – Persons with Parental Responsibility for a Disabled Child who Provide or Intend to Provide a Substantial Amount of Care on a Regular Basis for the Child

## Scope of the 2004 Act

### Assessments: people with parental responsibility for disabled children

71. Assessments of families with disabled children should be conducted in accordance with the statutory guidance set out in the *Framework for the Assessment of Children in Need and their Families*. This guidance emphasises the importance of a holistic assessment of family needs and avoiding piecemeal, repetitive or parallel assessments. Following the passage of the 2004 Act, the assessment should take account of the parent's ability to provide or continue to provide care for the child and consideration of whether they work, or undertake any education, training or leisure activity or wish to do so. This means that local authorities have a duty to ask carers about these activities and take their wishes into account when planning the care package. For example, the package may provide the possibility of freeing some leisure time for the carer and for other children in the family through a structured playtime with the disabled child, while social services provides services to run the house. The local authority must take assessments carried out under section 6 of the 2000 Act into account when deciding what services, if any, to provide under section 17 of the Children Act 1989.
72. Disabled children and their families should have access to the full range of child care options open to other families, and *Choice for parents: the best start for children* sets out the Government's commitment to improve child care for disabled children. Local authorities will have the central role in commissioning and co-coordinating the delivery of integrated early years and childcare services. The childcare strategy is particularly important for parents with disabled children, as lack of affordable and accessible child care is frequently cited as a reason why such parents are unable to go to work. When assessing the needs of disabled children and their families, social care staff should be aware of the range of options to enable those parents who wish to

participate in the work force to do so, and of the potential financial, emotional and social benefits to parents of working. Support to parents to help them to work could be an effective way of safeguarding and promoting the welfare of the child.

### **Duty to inform**

73. By virtue of the 2004 Act, where it appears to a local authority that it would be required to carry out a carer's assessment under the 2000 Act on being asked to do so by a person with parental responsibility for a disabled child, the authority must ensure that that person is informed that he or she may be entitled to such an assessment. This does not apply where the person has already been informed that he or she may be entitled to a carer's assessment or where the local authority has previously carried out such an assessment on his or her behalf in relation to the disabled child. Local authorities may consider developing an information strategy and working in partnership with local statutory and voluntary sector partners to help ensure that carers of disabled children are getting information about their rights in a consistent way. See paragraph 30 above for more detail on the local authorities' duty to inform carers of their right to an assessment and examples of good practice.

### **Co-operation between authorities**

74. As is the case for requests relating to carers of individuals aged 18 or over, where a local authority requests one of the public authorities listed below to assist it in the planning and provision of services for persons with a parental responsibility for a disabled child or for services for the disabled child, the authority must give due consideration to the request. The authorities are:
- other local authorities,
  - any local education authority,
  - any local housing authority,
  - and certain National Health Service bodies, including any Primary Care Trust, any NHS Trust or NHS Foundation Trust, and any Local Health Board
75. More detail about co-operation between authorities and what constitutes due consideration is available at paragraphs 33 to 36 above.

### **Services for families with a disabled child**

76. While the Children Act 1989 requires that a child be in need before services can be made available, this does not mean that the child needs protection. The Children Act 1989, section 17, sets out the responsibilities of authorities to provide services to children in need and their families in order to safeguard and promote their welfare.

Where there is a disabled child the local authority has an obligation to assist the family if they need help in bringing up their child. This obligation is laid down in Part III of the Children Act and is the basis in law for the provision of local services to disabled children and their families. It is the duty of local authorities to work in partnership with families to provide those services that will best meet the needs of the children. The provision of services that assist parents who need help in bringing up their children is often the most effective means of promoting the welfare of disabled children.

## Direct payments to people with parental responsibility for disabled children

77. People with parental responsibility for disabled children can sometimes find it difficult to access mainstream services such as child care, after school clubs and leisure activities. Families with disabled children may not think existing services provided or commissioned by their local authority are suitable for their child and believe that they can make arrangements for themselves which will be more beneficial. Services for disabled children should be designed to maximise the child's abilities and independence and give disabled children the opportunity to lead lives that are as normal as possible. Local authorities are reminded of the duty to offer direct payments to enable people with parental responsibility for a disabled child to arrange for the provision of services rather than rely on services provided by the local authority. *Direct Payments Guidance – Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England 2003* remains the primary source of guidance around the use of direct payments both for the carer and the cared for person.

## Transition to adulthood for the disabled child

78. Parents often face problems in supporting and preparing their children for an independent adult life, but people with parental responsibility for disabled children face an even wider-ranging set of issues than parents of non-disabled children. The transition to financial independence and independent living is not usually a single event, nor does it happen quickly. In some cases the young person at age 16 or 17 may wish, as part of the transition to adulthood, to take control of part or all of the direct payment that has to date been managed by the person with parental responsibility. Where there is a difference of view between children and their parents over such matters, provided that the children have sufficient understanding to make informed decisions, the local authority should give precedence to the views of the children.

79. The *Special Educational Needs (SEN) Code of Practice* requires schools (and Local Education Authorities where pupils are out of school) to ensure that a transitional plan is drawn up for those with statements of SEN in partnership with the young person, his or her parents, *Connexions* and other agencies including social services and health. This transition plan is drawn up following the annual review of the child's statement in school year 9 and the Code of Practice gives *Connexions* the role of overseeing its implementation. It is a key document for the agencies involved with the young person and should inform any other assessments of the young person, join up with other plans (such as a pathway plan) and should inform decisions made about direct payments to disabled young people.

### **Planning services in partnership with parents and children**

80. Existing guidance emphasises the importance of:
- the family as the natural and most appropriate place for children;
  - local authorities working in partnership with parents,
  - recognising that children are individuals with their own wishes and feelings, and
  - holistic family assessment taking account of the views of children and parents.
81. See the Assessment Framework, paragraphs 3.32 and volume 6 of the Children Act 1989 Guidance, paragraph 6.1.
82. Children Act guidance states that services “are intended to assist the parent and enhance, not undermine, the parent’s authority and control.” The guidance discusses the need to allow older children and young people to participate in decision making. It warns against making blanket assumptions that certain disabled young people are not able to participate in decision making. It is in the context of this guidance that parents, young people and local authorities will wish to consider in partnership who is best placed to manage part or all of the care package.
83. Whatever decisions are made when the child reaches age 16 or 17, people with parental responsibility for a disabled child may not continue to receive direct payments to purchase services that meet the needs of that child once the child reaches his or her majority. If they are going to continue in their caring role, however, such carers may be entitled to receive direct payments as an alternative to local authority directly provided carers’ services under the provisions of the 2000 Act. Carers’ services would be provided or commissioned/funded to support the parent carer in their caring role and may also help them maintain their own health and overall well-being, including the opportunity to have a life outside caring whilst ensuring the child’s needs are fully met.

84. It will be important for local authorities to respect the views of parents who have been managing the delivery of support for their child and take account of those views in setting in place any new arrangements once the young person reaches his or her majority. This will be particularly important where the young person is assessed as unable to manage direct payments (with or without support) as there will be an additional need to ensure that the impact of the loss of the direct payment option is minimised and that as far as possible continuity in service delivery is achieved. See also paragraph 78 above and the section on transition to adulthood in the *Carers and Disabled Children Act – Direct payments for young disabled people – Policy and Practice Guidance*.

### Further guidance on direct payments policy

85. Fuller information on direct payments and how they relate to people with parental responsibility for disabled children may be found in paragraphs 116 to 134 of the *Direct Payments Guidance – Community Care, Services for Carers and Children’s Services (Direct Payments) Guidance England 2003*. This document also provides overarching guidance on matters relating to the 2003 *Direct Payment Regulations* including guidance on developing, using and monitoring direct payments locally as well as advice relating to employing suitable people to work with children and criminal record checks.
86. Guidance for recipients of direct payments includes a *Guide to Receiving Direct Payments*, an *Easy Guide to Direct Payments* and a direct payments guide for parents.

### Short Term Break Voucher Schemes

87. The 2000 Act provides local authority social services departments with the option to run short term break voucher schemes. Short term break voucher schemes offer flexibility in the timing of carers’ breaks and choice in the way services are delivered to families with disabled children.
88. The *Carers and Disabled Children (Vouchers) (England) Regulations 2003* provide for the value of a voucher to be expressed in terms of either money or of the delivery of a service for a period of time. Time value vouchers *must* specify the service that is to be provided in order to allow the carer to take a break, although the vouchers are redeemable either against one provider or a group of providers offering a similar service. Money vouchers *do not* specify the service provider when the voucher is redeemed. Both types of vouchers allow flexibility about when to arrange for the service to be delivered. These Regulations also enable local authorities to make

vouchers available to people with parental responsibility for disabled children to secure services for the disabled child in order to allow the parent carer to have a break from caring.

89. Further guidance on short term break vouchers is available in *Carers and Disabled Children's Act 2000 – Vouchers for short-term breaks – Policy and Practice Guidance*, issued by the Department of Health.

## Complaints

90. The Children Act 1989 requires all local authorities to set up procedures for considering representations and complaints (Section 26). The range of complaints that may be considered is limited to the way the authority has discharged its functions to the child under Part III of the Act – that is, local authority support for children and families. Those entitled to make a complaint include: any child who is being looked after or who is in need; the child's parent; anyone else who is not a parent but has parental responsibility for the child; any local authority foster parent; anyone else that the local authority considers has a sufficient interest in the child's welfare to warrant the authority's consideration. The complaints procedure must have an independent element and be publicised. For further details see also the *Children Act Regulations and Guidance*, Volume 6 (Children with Disabilities) at Chapter 14.

## Part IV – Glossary of Terms

### **Carer**

For the purposes of the 2000 Act the term “carer” means a person (aged 16 or over) who provides or intends to provide a substantial amount of care on a regular basis for an adult or a disabled child. The person may or may not be a relative and may or may not be living with the person for whom they are caring.

The 2000 Act excludes from the definition of a carer, paid care workers and volunteers from a voluntary organisation. “Voluntary organisation” has the same meaning as in the National Assistance Act 1948. The exclusion extends to anyone who is providing personal assistance for payment, either in cash or kind.

### **Young Carer**

A young carer is defined as any carer below the age of 18.

### **Children in need**

The definition of children in need in section 17(10) of the Children Act 1989 states that “a child shall be taken to be in need if:

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

Section 17(11) of that Act sets out that a child is disabled if he 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 or such other disability as may be prescribed”.

In this context, ‘development’ means physical, intellectual, emotional, social or behavioural development. ‘Health’ means physical or mental health.

<b>Fair Access to Care Services</b>	Guidance on fair access to care services was issued by the Department of Health in 2002, and provided a framework to enable authorities to determine eligibility for services in a fairer and more consistent way.
<b>Framework for the Assessment of Children in Need and their Families</b>	The Guidance describes the Assessment Framework and the Government's expectations of how it will be used. It reflects the principles contained within the United Nations Convention on the Rights of the Child, ratified by the UK Government in 1991 and the Human Rights Act 1998.
<b>Parental Responsibility for a Disabled Child</b>	In the Children Act "parental responsibility" means all the rights, duties, powers, responsibilities and authority of parents in relation to the child and his property. People other than parents, for example, grandparents or guardians, can have parental responsibility for a child. Further guidance on parental responsibility can be found in <i>The Children Act 1989 Guidance and Regulations Volume 1</i> .
<b>Principles of Part III of the Children Act</b>	Terms used in section 6 of the 2000 Act have the same meaning as in Part III of the Children Act 1989. Section 6 works in tandem with section 17 of the Children Act 1989 ensuring that the general principles of Part III of the Children Act apply. Services provided under section 6 of this Act must therefore safeguard and promote the welfare of the child.
<b>A Parent's Guide to Direct Payments</b>	Guidance on direct payments aimed at parents was issued by the Department of Health in 2003 and provided some background on who might be eligible to receive direct payments, what they can be used for, how to get access to them and other issues to consider such as the possibility of employing someone to provide support.

# Annex A – Related Policy Initiatives

In considering this guidance local authorities will wish to keep in view other policy initiatives that impact on carers, parents and those they care for. Some major current and planned policy initiatives are set out below.

## **Fair Access to Care Services (FACS)**

The Department of Health issued statutory guidance on fair access to social care services in 2002. The guidance provides a common framework for determining eligibility for adult social care services provided or purchased by authorities with social services responsibilities. It also sets out general principles by which assessments should be conducted to ensure they are a fair process for reviewing adult service users' needs and continuing eligibility for support. Implementation by authorities should lead to fairer access across the country and the provision of support to promote independence.

## **Implementation of Health Act 1999 – Partnership Arrangement**

To provide the co-ordinated services users and carers need, local authorities need to work closely with the NHS. The Health Act 1999 enables local partnership arrangements between NHS and local authorities that remove some of the barriers to providing fully integrated services which are user and carer focussed.

## **Improving the Life Chances of Disabled People**

This report was published by the Prime Minister's Strategy Unit in January 2005 in conjunction with the Department for Work and Pensions, the Department of Health, the Office of the Deputy Prime Minister and the Department for Education and Skills. It sets a target that 'by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.'

## **Independence, Well-being and Choice**

The Green Paper on the future of social care for adults in England sets out a vision of services that are person-centred, proactive and seamless, improving choice for people who use services and promoting their lifelong well-being. It focuses specifically on carers and their contribution in one chapter, exploring an extension to the range of support provided to carers, and a more flexible approach in looking at the balance of needs and services.

## **Caring about Carers: a national strategy for carers**

*Caring about Carers* was published in 1999 and was developed with carers and the organisations that represent them. It set out better ways to help carers, including those in employment and young carers. The strategy also identified key factors in supporting sustainable caring, one of which was the need for legislation to enable local authorities to provide services to carers.

## **General Principles of Assessment**

Both the *National Service Framework for Mental Health* and the *National Service Framework for Older People* cover assessment and related aspects of care management. In addition, the package of guidance relating to the Carers and Disabled Children Act 2000 includes a *Practitioner's Guide to Carers Assessments*. *Fair Access to Care Services* also contains a section on general principles of assessment (see above).

In dealing with the needs of children (including those aged 16 and 17) the *Framework for the Assessment of Children in Need and their Families* remains the main source of guidance for local authorities.

## **Choosing Health**

*Delivering Choosing Health* outlines how the commitments identified in the public health white paper *Choosing Health: making healthier choices easier* will be delivered at national, regional and local level across all sectors. New services to improve mental and emotional well-being by supporting parents and carers and improving parent-child relationships, as well as supporting carers and promoting social inclusion through initiatives to engage communities, are cited as "big wins" (key interventions most likely to improve health).

## **Standards for Better Health (within National Standards, Local Action, July 04)**

From April 2005, a new performance framework for NHS and social care – *Standards for Better Health* – sets out the level of quality all organisations providing NHS care in England will be expected to meet or aspire to meet. Within this framework there are standards specifically relating to carers:

- Core Standard 13 – health care organisations have systems in place to ensure that staff treat patients, their relatives and carers with dignity and respect
- Core Standard 14 – health care organisations have systems in place to ensure that patients, their relatives and carers:
  - have suitable and accessible information about, and clear access to, procedures to register formal complaints and feedback on the quality of services

- are not discriminated against when complaints are made, and
- are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery
- Developmental Standard 8 – health care organisations continuously improve the patient experience, based on the feedback of patients, carers and relatives
- Developmental Standard 9 – patients, service users and, where appropriate, carers receive timely and suitable information, when they need or want it, on treatment, care, services, prevention and health promotion, and are:
  - encouraged to express their preferences, and
  - supported to make choices and shared decisions about their own health care
- Core Standard 17 – the views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving health care services
- Core Standard 22 – Healthcare organisations promote, protect and demonstrably improve the health of the community served, and narrow health inequalities by:
  - Co-operating with each other and with local authorities and other organisations

### **NHS Improvement Plan**

The *NHS Improvement Plan*, published in June 2004, sets out the priorities of the NHS up to 2008 and supports the ongoing commitment to a 10 year reform process set out in the *NHS Plan*. It discusses the ways in which social care can play a part in meeting health needs, particularly for patients with long term conditions, and addresses:

- the need for social care to be person centred and personalised
- the need for proactive services as well as – and in order to prevent – crisis intervention
- the role that preventative services can play in maintaining independence at home
- how the Single Assessment Process and Direct Payments will be vital to meeting these aims

### **National Service Framework for Mental Health (NSFMH)**

The *Mental Health National Service Framework* set a specific standard (Standard 6) for carers of people with severe mental illness, for the first time emphasising the essential part that families, friends and natural support systems have to play in the support and recovery process of an individual with mental health problems. The NHS Plan chapter on Mental Health took this further by specifying investment in carers' support (and indeed new services for women). Following this, *Delivering Race Equality in Mental Health Care*, an

action plan for reform inside and outside NHS mental health services over the next five years, was published in January 2005. This programme of work is designed to help local services understand how to oppose discrimination and provide effective mental health care in a diverse society. Work is being taken forward in 17 early implementation sites across England

### **National Service Framework for Older People (NSFOP)**

The *National Service Framework for Older People* sets for the first time clear national standards defining the care and treatment that older people can expect. Standard Two (Person Centred Care) aims to ensure that older people are treated as individuals and receive appropriate and timely packages of care. This includes providing coordinated and integrated services, and involving and supporting carers whenever necessary.

### **National Service Framework for Children, Young People and Maternity Services (2004)**

The Children's National Service Framework develops new national standards for the NHS, social services and their interface with education. It builds on current Government programmes to develop an integrated approach to supporting disabled children and/or children with special education needs, ensuring that care is designed around the needs of individual children and their families. The NSF includes exemplar diagrams illustrating optimum approaches to delivering services in a number of different areas. One of these is about children with autism and will show how families should receive multi-agency early intervention and support based on their needs.

### **National Service Framework for Long-term Conditions (NSFLTC)**

The *National Service Framework for Long-term Conditions* was launched in March 2005. It aims to transform the way health and social care services support people to live with long-term neurological conditions. Key themes are independent living, care planned around the needs and choices of the individual, easier, timely access to services and joint working across all agencies and disciplines involved. The principles of the NSF are also relevant to service development for other long-term conditions. The NSF has a number of Quality Requirements, one of which is supporting family and carers of people with long term neurological conditions. This suggests that there is scope to:

- identify more carers who need support (eg carers from black and minority ethnic communities report significant problems in accessing carers' services)
- develop voluntary sector and local authority carers' projects that focus specifically on the needs of carers of people with long-term neurological conditions

- improve the training of health and social care professionals in awareness of the needs of carers, in the effects of cognitive impairments and in person-centred care planning.

### **Valuing People: A New Strategy for Learning Disability for the 21st Century**

This white paper was published in March 2001 and set out a programme of action for improving services based around four key principles: civil rights, independence, choice and inclusion. *Valuing People* takes a life-long approach, beginning with an integrated approach to services for disabled children and their families, and then providing new opportunities for a full and purposeful adult life. It also includes a comprehensive section on supporting the carers of people with learning disabilities (chapter 5).

### **Delayed Discharges**

The Community Care (Delayed Discharges) Act 2003 ensures that the needs of carers are assessed and services or equipment is provided by local authorities to support individuals and their carers on discharge from hospital. The legislation, which makes provision of equipment – including assistive and telecare technologies – free of charge to individuals, also applies to carers.

### **Guidance on the Single Assessment Process for Older People**

The Single Assessment Process (SAP) for older people was introduced as part of the *Older People's National Service Framework* in 2001. Implementation of the SAP is intended to ensure a person-centred approach to assessment and care planning for service users. Full involvement of individuals and their carers in both assessment and care planning is recognised good practice.

### **Quality and Choice for Older People's Housing – A Strategic Framework**

A strategic framework for housing for older people was jointly published by the Department of Health and the Department of Environment Transport and the Regions in January 2001. This set out a vision for older people's housing and housing-related support to enhance quality and choice and promote greater linkage between housing, social care and health policies to encourage new solutions in promoting independence. A 'Housing and Older People Development Group' (HOPDEV) was also set up at this time to act as champions for this framework and help enable Government and all those working with older people in housing, care and support to ensure that new and existing policies consider the diverse needs of older people. *Quality and Choice for Older People's Housing – the story so far* was published in November 2002 to give an update on actions and progress, particularly in relation to the work of HOPDEV. Work currently being undertaken by HOPDEV includes looking into ways to develop advice, information and advocacy services for older people and their carers to help them in making choices about housing, care and support options.

## Education

Support should be provided to disabled or ill parents so that young carers do not assume levels of caring responsibilities that may prevent them achieving their full potential at school. Further guidance about how schools might help young carers is in Circular 10/99 School Inclusion: Pupil Support, para 3.10 to 3.12. The DfES *Programme of Action Meeting Special Educational Needs* describes a range of measures to work in partnership with parents to achieve excellence for all to develop a more inclusive education system, and work in partnership with other agencies to strengthen support for children with special needs. The stresses on parent carers of disabled children are reduced when the children's social, health and educational needs are met in an integrated and responsive way.

## Children and Young People

On 1 December 2004 the Government published *Every Child Matters: Change for Children* – a national framework for local action to improve five key outcomes: being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic well-being. These five outcomes – which are at the heart of the Children Act 2004 – are essential to well-being in childhood and later life. The Government's ambition is to improve these outcomes for all children and to narrow the gap in outcomes between those who do well and those who do not.

Each local authority – working with its partners – will lead a programme of change based on local priorities and designed to deliver improved outcomes for local children and young people.

More information on *Every Child Matters: Change for Children* can be found at [www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk) Key policy documents can also be downloaded from this site.

## Choice for parents, the best start for children: a ten year strategy for childcare

Published in December 2004, this report set out the Government's vision to ensure that every child gets the best start in life and that parents have choice over balancing work and family life. It set targets around increasing maternity leave, flexible, affordable and appropriate childcare for children up to the age of 14, and developing a highly-skilled childcare workforce.

## **Early Support**

*Early Support* is a Government programme (formerly known as Early Support Pilot Programme) to improve the delivery of services to disabled children under three and their families. Early Support promotes service development in partnership with education, health and social services, voluntary organisations and people who use services. It is putting into practice the principles outlined in the Government's guidance document *Together from the Start*, which was published in May 2003. This guidance recognises that when children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for children and families.



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