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Carers and Disabled Children Act 2000

*Carers and
people with parental responsibility for
disabled children*

Policy Guidance

Carers and Disabled Children Act 2000

Carers and people with parental responsibility for disabled children

Policy Guidance

Foreword

There are an estimated 5.7 million carers in Great Britain. One in six households – 17 per cent – contains a carer. In England an estimated 1.4 million of those carers devote at least 20 hours a week to caring; of those, more than 700,000 care for 50 hours or more.

Most caring is based on close personal relationships that pre-exist the caring role and within those relationships carers have a wide range of different caring responsibilities. They may be helping a frail parent to continue to live in their own home, or be bringing up a child with a disability. They may be supporting a partner with a severe mental health problem, or be assisting an adult son or daughter with a learning or physical disability to live independently.

Whoever they care for, carers all need the opportunity to make informed choices about the extent of their caring role, to maintain their own health and well being and to have sufficient freedom to maintain relationships, employment, interests and other commitments alongside their caring responsibilities. The Government is committed to ensuring that carers are supported to achieve these aims.

The National Carers Strategy has achieved much in improving carers' access to breaks services, to information and to support. Now, for the first time under one piece of legislation, the Carers and Disabled Children Act 2000 gives a right to an assessment for carers of adults and people with parental responsibility for disabled children. This right to an assessment gives local councils the opportunity to provide carers with services to meet their own assessed needs. This is a very important change to the way social services departments may provide support to carers.

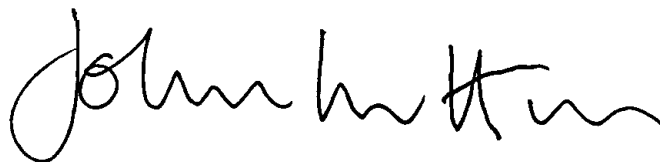
Carers after all are the ones who know how best they may be supported in their caring role. That is why 'services to carers' are not defined in the Act. Councils will have discretion to meet carers' needs with any service that will genuinely help them to continue to care and to maintain their health and wellbeing. This gives social services departments much greater scope to be flexible and innovative in the way they provide support to those within caring relationships.

It is important for carers, who give so much, that they have as much control over how they are able to organise their time as possible. That is why the Act, in addition to the power for local councils to provide carers with services also allows carers the option of direct payments to purchase for themselves services to meet their assessed support needs. In the same way, people with parental responsibility for disabled children will be able to purchase services for the disabled child and family.

But before any of this can happen we have to make contact with carers. We know that many carers do not see themselves as such so do not come forward for help. We also know that they are sometimes 'invisible' to staff assessing the people they care for. That is why we have made available a leaflet: *How to get help in looking after someone - A Carer's Guide to A Carer's Assessment*.

We are asking local councils to make sure that any carer whose care is being taken into account during an assessment of the needs of the person they care for is given or sent one of these leaflets. That way they will at least know that the council thinks they are a carer, and what a carer's assessment has to offer them. This leaflet, drawn up with the help of carers' organisations, is another way of trying to give the carer more control of their situation. It will help them to request an assessment of their needs there and then, or later when they feel the time is right.

The Carers and Disabled Children Act 2000 is a crucial part of our National Carers Strategy towards meeting the Government's commitment to value the contribution that carers make in our communities. We want carers to enjoy more flexible support than they have before. And to do this we must listen and go on listening to what they are telling us about their needs.

A handwritten signature in black ink, appearing to read 'John Hutton', with a stylized, cursive script.

John Hutton
Minister of State for Social Services
March 2001

Carers and Disabled Children Act 2000

Policy Guidance on the provisions of the Act as they affect:

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

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Part I Overview

Introduction

- 1 The Carers National Strategy document “Caring about Carers”, published on 8 February 1999 highlighted the need for legislation to enable local councils with social service responsibilities (local councils) to provide services direct to carers.
- 2 The Carers and Disabled Children Act 2000 (“the Act”) enables local councils to offer carers support. Services to carers are not defined as such. The local council may provide any services which, in their view, will support the carer in their caring role and help them to maintain their own health and well being. These services may take any form.

Purpose

- 3 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 councils in exercising the power given them by the Act as it affects:
 - carers (aged 16 or over) who provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over;
 - 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.

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 councils.

- 4 The accompanying practice guidance advises on *how* local councils might implement the Act, while the practitioner’s guide to assessment sets out carer assessment good practice. The three pieces of guidance should be read together.

Context – Policy Aims and Objectives

- 5 The Government's aim is to support people who choose to care in their caring roles and to help them maintain their own health and well being. To meet this aim local councils have the power to supply certain services direct to carers following assessment. Carer's have a right to an assessment of their needs even where the person cared for has refused an assessment for, or the provision of, community care services, provided the person cared for would be eligible for community care services.
- 6 Persons with parental responsibility for a disabled child (usually the parents) also have a right to ask for an assessment. The local council must take that assessment into account when deciding what services, if any, to provide under section 17 of the Children Act 1989 to support the disabled child and the family.
- 7 The Government has given local councils the power to make direct payments to carers (including 16 and 17 year old carers receiving support under the Act) to meet their own assessed needs. In addition local councils may make direct payments to people with parental responsibility for a disabled child to purchase services to meet the assessed needs of the disabled child and family. The aim of direct payments is to allow recipients to make more decisions for themselves creating greater flexibility in the way their assessed needs are met and thus provide opportunities for families to have more control over their own lives. So long as the local council is satisfied that the assessed needs of the carer or disabled child and family will be met through the arrangements the carer or parent makes using the direct payment, the local council is relieved of its responsibility to arrange those services.

Part II

Carers (Aged 16 Or Over) Who Provide Or Intend To Provide A Substantial Amount Of Care On A Regular Basis For Another Individual Aged 18 Or Over

Scope of the Act

Right of carers to assessment

- 8 Carers age 16 or over are eligible for an assessment of their ability to provide care and continue to provide care
- where they provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over
 - and the local council is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services.

This right exists even where the person cared for has refused an assessment by the local council social services department or has refused the delivery of community care services following assessment.

Ensuring carers are aware of their right to an assessment

- 9 When assessing a disabled person and taking account of support provided by a carer, the assessor should inform the carer of their right to ask for an assessment. To ensure that the carer has been made aware of this right the assessor should give the carer a copy of the Department of Health leaflet “*How to get help in looking after someone - A carers guide to a carers assessment*”.

Where the cared for person refuses assessment or services

- 10 Where a satisfactory level of information about the carer and the cared for person is already available to the local council and the cared for person's views on contact with social services is well known, the local council may wish to proceed with an assessment of that carer's needs without further enquiry. This might be because the cared for person has recently been assessed under community care legislation but has refused services following assessment.

- 11 In circumstances where the cared for person has not been assessed the local council should develop local protocols and procedures to ensure they are able to make reasoned judgements about whether the conditions set out in paragraph 8 above that give rise to the right of assessment have been met.
- 12 In most situations where a carer is requesting an assessment and the local council has no record of a recent community care assessment having taken place, social services should, in the first instance, approach the cared for person to ascertain if they are willing to be assessed.
- 13 Where the cared for person remains unwilling to be assessed local councils should gather enough supported information from the carer to make a reasoned judgement about the need to conduct a carers assessment. This might involve making arrangements with local GPs, carers' support centres or carers' voluntary organisations, where they are willing to enter into such agreements, to accept referrals from them. These agreements would be likely to include that the referring persons or organisations will only refer for a carers assessment people who are likely to be eligible carers as defined in paragraph 8 above. Such arrangements would assist local councils in their decision making function while respecting client/patient confidentiality, yet also providing a level of supporting information for the claims of the carer.

Links with Carers (Recognition and Services) Act 1995

- 14 When conducting an assessment under the Act, the local council may take into account, so far as it considers it to be material, any assessment the carer may have had under the provisions of the Carers (Recognition and Services) Act 1995. This may be particularly helpful during implementation of the Act when reviewing the possible service needs of carers already known to social services. In the less likely event that the local council will wish to conduct an assessment of a carer age 16 or over eligible for support under the provisions of the Act under the provisions of the Carers (Recognition and Services) Act 1995, the link between the Act and the 1995 Act also applies in the opposite direction.

Disabled Persons (Services Consultation and Representation) Act 1986

- 15 If the impact of the caring role on the carer is such that their input is not deemed to be equivalent to a substantial amount of care on a regular basis, the impact of the caring role on the carer should still be taken into account and recorded as part of the assessment of the person they care for. Section 8 of the Disabled Persons (Services Consultation and Representation) Act 1986 requires the local council to have regard to the ability of the carer to provide or continue to provide care when deciding what services to provide to the disabled person.

A carer centred approach to assessment

- 16 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 being specific and relevant to the individual carer, also meet the test of supporting the carer in their caring role or helping them to maintain their own health and well being. Fuller guidance on this can be found in the practice guidance and the Practitioners Guide to a Carer's Assessment. Local councils will also need to keep in view the Mental Health National Service Framework (MHNSF) and the National Service Framework for Older People.

Substantial and regular

- 17 In the first instance, the local authority will begin the assessment of the carer's needs with regard to the sustainability of their caring role by satisfying themselves that the person cared for is someone for whom it may provide or arrange for the provision of community care services. See paragraphs 8 to 13 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 Act.
- 18 Once the local council 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.

- 19 There is no definition in the 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.

Any such judgement should recognise that, for example, people caring for those with mental health problems have responsibilities that are not necessarily based on physical tasks. Further guidance on whether a person is providing substantial and regular care may be found in Practice guidance on the Act.

Promoting and safeguarding the welfare of carers age 16 or 17

- 20 The Carers and Disabled Children Act 2000 will only rarely be used by councils looking at the needs of 16 and 17 year old carers. In most circumstances the local council should ensure that the person cared for is receiving sufficient services so that a young person age 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 council should ensure that such young peoples’ futures are not adversely affected by caring responsibilities that may undermine their own need to participate fully in education, training 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. Where local councils are satisfied that the child’s welfare can be promoted and safeguarded as they take on a substantial caring role it could decide, in these rare circumstances, that it would be more helpful to a young person to be assessed and receive services under the provisions of this 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

- 21 Following assessment the best outcomes for both cared for and carers are still likely to result from the provision of good quality community care services for the person cared for. In addition, the local council must consider the information gathered and decide whether to provide services to the carer.
- 22 Services to carers are not defined as such in the Act. The local council may provide any services they see fit to provide and which in their view meets one of two tests:
- that it will help the person care, or
 - that it will help to maintain the carer's own health and well being.

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.

- 23 It follows that there are some services that could be delivered as carers' services under the Act that could also be delivered as community care services. It is for the local council to decide whether they are providing a service to support the carer's need (a carers service) or a service to meet the care needs of the person cared for (a community care service). The local council's decision 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 council 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

- 24 Services provided to a person with a carer will, following assessment, usually be provided as community care services as they are provided for services users without carers. In some circumstances local councils 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 or the delivery of services to them in their own right. This flexibility is limited to services that could be provided to the person cared for by way of community care

legislation. In addition such services may not, except in prescribed circumstances, include anything of an intimate nature. None of this may happen unless both the carer and the person cared for agree that the service is to be delivered in this way. See also paragraphs 26, 27, 28 and 29 below '*Services of an intimate nature*' and '*Prescribed circumstances*'.

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

Services of an intimate nature

- 26 Regulations define services of an intimate nature as including such things as:
- lifting, washing, grooming, feeding, dressing, bathing, toileting, administering medicines or otherwise having physical contact with the person cared for; or
 - assistance in connection with washing, grooming, feeding, dressing, bathing, administering medicines or using the toilet; or
 - supervising the cared for person whilst they are dressing, bathing, or using the toilet.

The purpose of defining in regulations what services of an intimate nature are is to prevent any services being delivered to unwilling disabled or frail older people. Therefore local councils will also want to ensure that the circumstances of the person cared for, for example his/her gender, culture or religious beliefs, mental health needs, age, or family life and way of living, are taken into account, and that any service they are considering providing is not inappropriate. For example, in some circumstances, being asked a personal question; discussing someone's psychological concerns; their relationships with others; or generally being communicated with by someone unfamiliar may be regarded as embarrassing or intrusive.

Prescribed circumstances

- 27 Regulations set out prescribed circumstances when 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 carers service as set out in paragraph 20 above. The purpose of the flexibility set out in the regulations is to ensure that cared for people will get help with intimate tasks if they change their mind while a carers' service is being delivered to them, or that appropriate help will be provided in emergency situations.
- 28 Regulations prescribe such circumstances as being where a service is being delivered to the person cared for, and
- a) during the delivery of that service the person cared for asks the person delivering the service to provide a service of an intimate nature; or
 - b) the person cared for 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 person cared for 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 the likelihood of serious personal harm to the person cared for is imminent.
- 29 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. On receipt of information from the service provider that an intimate service had been requested by and delivered to the cared for person the local council 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

- 30 The Act enables local councils to charge carers for the carers' services provided to them. This is achieved by means of an amendment to Section 17 of the Health and Social Services and Social Security Adjudications Act 1983. It will be for each local council to decide whether to make charges for non-residential services and if so how much to charge. In exercising these powers to make charges, local council should have regard to that person's ability to pay. Section 17(3) of the Health and Social Services and Social Security Adjudications Act 1983 gives any carer or cared for person the right to ask for a review of the assessed charge. Further guidance on reviews is given in the guidance on charges for non-residential social services.
- 31 Carers may not be charged for community care services provided to the people they care for. This prohibition includes the additional community care services provided to enable carers to take a break from their caring role. People cared for may not be charged for the carers' services provided to their carers. This includes services provided as carers' services but delivered to cared for people as set out in paragraphs 24 and 26 above '***Carers' services that may be delivered to cared for people***'. Any local policy on charging for non-residential services should be consistent between users of carers' services and users of community care services. If both user and carer are being assessed for a charge for their respective services (e.g. if they are spouses or partners), the local council 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 will be liable to pay any charge.
- 32 More detailed guidance on how councils should assess the reasonableness of charges will be issued by the Department of Health in 2001.
- 33 Where services are provided to 16 and 17 year old carers, councils 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 broadly in line with the charging provisions for services for 16 and 17 year olds under the Children Act 1989.

Direct payments

- 34 The Community Care (Direct Payments) Act 1996 gives local councils the power to offer people cash payments as an alternative to arranging social care services to meet their assessed support needs. Direct payments will offer carers the opportunity to be innovative and flexible in how they arrange the delivery of services to them to meet their assessed needs. A carer might choose to use a direct payment to employ someone they know to clean for them rather than making use of a local council arranged service. Subject to any exceptions prescribed in regulations, all carers will be eligible for direct payments.

Information

- 35 Making information about direct payments readily available might include, where appropriate, providing information in formats which are accessible to people with different forms of impairment and to people whose first language is not English. For carers who are themselves disabled the provision of accessible information will be necessary in order to comply with the Disability Discrimination Act 1995. It will usually help carers who are considering the direct payment option to be put in touch with a support group for direct payment users, local voluntary organisations with developing expertise in this area or local centre for independent living.

Close relatives

- 36 Regulations prevent carers using direct payments to secure services from their partner (i.e. the other member of a married or unmarried couple). Nor may they secure services from a close relative living in the same household. A close relative in this context is a parent, parent-in-law, aunt, uncle, grandparent, son, daughter, son-in-law, daughter-in-law, step-son or daughter, brother, sister or the spouse or partner of any of these.
- 37 In addition, local councils should not allow people to use direct payments to secure services from a close relative living elsewhere or from someone else living in the same household as the direct payment recipient. This restriction applies where the relationship between the two people is primarily personal rather than contractual, e.g. if the people concerned would be living together regardless of any employment relationship. A local council may decide that an exception to this general rule is justified, if it is satisfied that that is the most appropriate way of securing the relevant services.

Direct payments for carers age 16 and 17

38 While direct payments may be offered to all carers assessed as needing support under the Act, except those specified in regulations, it is unlikely that there will be many situations where such an arrangement would be the best option for a young carer aged 16 or 17 receiving services under the provisions of the Act. The facility is available to allow for flexibility in the small number of circumstances where a 16 or 17 year old is choosing to undertake a substantial caring role for a period and that decision is supported by the local council. It could in some circumstances be more helpful to the young carer to receive a direct payment, for example, to allow them to arrange for carer services to be delivered in such a way as to minimise any disruption to their education that would result from their decision to care. For further guidance please see *The Framework for the Assessment of Children in Need and their Families* paragraph 3.61.

Contracting with a minor

39 The only contracts which are binding on minors are contracts for “necessaries” i.e. necessary goods and services. It is ultimately for the court to decide, but services purchased by 16 or 17 year old carers to meet their assessed needs for social services support are likely to be deemed as “necessaries” and contracts of employment entered into by them using a direct payment would therefore be enforceable in the same way as any others. The responsibilities of employers set out in employment legislation (eg the national Minimum Wage Act 1998) apply regardless of the employer’s age.

Services that may be purchased using a direct payment

40 Direct payments are an alternative to local council social services directly provided services. Direct payments will allow carers to purchase the services they are assessed as needing as carers to support them in their caring role and to maintain their own health and well being. Carers may not receive a direct payment to purchase community care services to meet the assessed needs of the person they care for. The person to whom the direct payment relates must remain in control of the arrangements, and remain accountable for the way in which the direct payment is used. The 1996 Act does not allow social services departments to make payments to third parties to manage on behalf of the service user where the user is not in control. Fuller information may be found in the Community Care (Direct Payments) Act 1996 – Practice Guidance.

- 41 Overarching guidance on matters relating to the 1996 Act may be found in The Community Care (Direct Payments) Act 1996 – Policy and Practice Guidance. This includes guidance on best value and monitoring. Guidance for recipients of direct payments includes a Guide to Receiving Direct Payments and an Easy Guide to Direct Payments. The former contains advice relating to employment.

Short Term Break Voucher Schemes

- 42 The Act provides for local council social services departments to run short term break voucher schemes. Short term break vouchers will enable cared for people to make arrangements for the additional support they need when their carer needs a break. Short term break voucher schemes will offer flexibility in the timing of carers' breaks and choice for cared for people in the way community care services are delivered to them while their usual carer is taking a break.
- 43 Under the Act regulations are required to make provision for local councils to issue short term break vouchers. Regulations may, in particular provide for the value of a voucher to be expressed in terms of money or of the delivery of a service for a period of time, and for the person who supplies a service against a voucher, or for the arrangement under which it is supplied to be approved by the local council. Regulations may also provide for vouchers to be issued to carers if that is the wish of the person cared for and for a maximum period during which a service can be provided against a voucher.
- 44 Fuller guidance on the development of local voucher schemes will be issued at the time such regulations are introduced.

Complaints procedure

- 45 Local councils are required to operate a procedure for considering any representations (including any complaints) which are made to them with respect to the discharge of their social services functions or about 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 may make complaints about any action, decision or apparent failing of the local council, but not about services which they have secured from independent providers (including people they employ directly) using direct payments. 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 Act

Assessments: people with parental responsibility for disabled children

- 46 A person with parental responsibility for a disabled child who provides or intends to provide a substantial amount of care on a regular basis for the child has the right to ask the local council for an assessment of their ability to provide (and to continue to provide) care for the child. The local council must take that assessment into account when deciding what services, if any, to provide under section 17 of the Children Act 1989.
- 47 For persons with parental responsibility for a disabled child an assessment should be conducted in accordance with the 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.
- 48 When conducting an assessment, the local council may take into account, so far as it considers it to be material, any assessment the person may have had under section 1(2) of the Carers (Recognition and Services) Act 1995. The link between the Act and the 1995 Act also applies in the opposite direction, but see also para 34 above.

Services for families with a disabled child

- 49 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 councils to provide services to children in need and their families to safeguard and promote their welfare. Where there is a disabled child the local council 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 councils 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

- 50 The responsibilities of people with parental responsibility for disabled children are sometimes made more arduous by the difficulty of accessing mainstream services, for example child care, after school clubs and leisure activities. Families with disabled children may not think existing services provided or commissioned by their local council 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 councils may 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 funded by the local council.

Eligibility for direct payments

- 51 Direct payments to people with parental responsibility for a disabled child will be provided within the framework of Part III of the Children Act 1989 which requires local council to provide a range of services to promote and safeguard the welfare of children in need. All people with parental responsibility for a disabled child who have been assessed for Children Act support for the disabled child and family will be eligible for direct payments. But see also paragraph 66 below ***'Ability to manage a direct payment'***.
- 52 Local councils should work in partnership with parents following Children Act 1989 Guidance. Councils should only exercise their discretion to arrange a direct payment for a parent of a disabled child when they are satisfied that the parent is a person who will make arrangements that are designed to safeguard and promote the welfare of the child. So long as the local council is satisfied that the assessed needs of the disabled child and family will be met through the arrangements the parent is making using the direct payment, the local council is relieved of its responsibility to arrange those services.

Councils retain their responsibilities under the Children Act to assess and, where appropriate, review the needs of disabled children and their families in the normal way.

Information

- 53 The Children Act 1989 (Schedule 2, para 1) requires local councils to provide information about services available in their area. It will be essential that families have information about the full range of service when considering the option of direct payments, including the procedures local councils should follow in appointing care staff and in enquiring into allegations of child maltreatment.
- 54 Making information about direct payments readily available might include, where appropriate, providing information in formats which are accessible to people with different forms of impairment and to people whose first language is not English. For parents who are themselves disabled the provision of accessible information will be necessary in order to comply with the Disability Discrimination Act 1995. In cases where there is a possibility that the person with parental responsibility for a disabled child will be offered direct payments, it will usually help them to be put in touch with a support group for direct payment users, local voluntary organisations with developing expertise in this area or local centre for independent living.
- 55 Local councils should make clear the steps that people with parental responsibility for a disabled child ought to take to satisfy themselves that the person offering help with the care of their child is a suitable person. “Working Together to Safeguard Children” (Department of Health et al, 1999)(para 6.27) comments that “the available UK evidence on the extent of abuse among disabled children suggests that disabled children are at increased risk of abuse.” It is important that people with parental responsibility for disabled children are fully alerted to any risks of abuse and provided with advice to minimise those risks.

Purchasing intimate care for a disabled child using a direct payment

- 56 Direct payments may be used by parents to purchase services of an intimate nature to meet the assessed needs of their disabled children. However, as children mature local councils may wish to encourage parents to give greater weight to the child’s views about how their intimate care needs are to be met.

Short term breaks

- 57 Many parents will wish to use a direct payment to arrange services in the home or improve access for their child to services in the community. Also, people with parental responsibility for disabled children may want to use a direct payment to arrange short term breaks for their child. Such breaks usually serve two purposes, both allowing the parents more time for other activities, for example with their non-disabled children, and affording the disabled child an opportunity to make new friends and participate in new activities. Parents may look to an established voluntary organisation to provide such breaks either in foster families or residential homes or they may wish to make their own arrangements. Where parents are making their own arrangements, for example to provide breaks at home the considerations set out in paragraphs 56 and 58 apply.

Criminal records checks

- 58 The Care Standards Act 2000 enables a person who is considering employing an individual to care for their child, where that care is funded by a direct payment, to ask the local council to carry out checks under the Protection of Children Act via the Criminal Records Bureau. When the person with parental responsibility requests such a check the local council has a duty to comply. Details of how these provisions will operate when the Criminal Records Bureau is established are set out in paragraphs 60 to 62 below.
- 59 Currently local councils if requested to do so by a parent may apply direct to the Department of Health for a check against the Protection of Children Act list to be undertaken. No fee will be payable. In addition until such time as the Criminal Records Bureau is established local councils will wish to continue their present arrangements for seeking criminal records checks.
- 60 An individual wishing to work with the child will make the application for a check to be carried out. The application will be counter-signed by the local council. A fee is required for each background check. The individual making the application for employment will normally be asked to pay the fee.

- 61 Local councils may want to clarify with those who request a check that it is in the council's discretion whether or not to make a direct payment. A parent's insistence on employing an individual who has been found to be unsuitable following such a check will be a factor in the council's decision whether to exercise its discretion.
- 62 When parents have chosen to ask for a check to be carried out, they should be advised to continue to receive services from their local council or current provider, or, in the interim, contract with a registered agency for the services they need to meet the assessed needs of the disabled child and family until the prospective candidate for employment is approved.
- 63 Local councils may also refer to the Protection of Children Act 1999 (PoCA) list a relevant individual the authority considers guilty of a misconduct that harmed a child or placed a child at risk of harm. A relevant individual is one who is or has been employed to provide care to a child and that employment is funded by a direct payment under section 17A of the Children Act.
- 64 Local councils should not arrange a direct payment for a person with parental responsibility for a disabled child unless they are satisfied that the support purchased with the money is designed to safeguard and promote the welfare of the child. Under section 1(6) of the 1996 Act the local council is empowered to recover all or part of a direct payment where it is not satisfied that it has been used for the purpose for which it was intended or that the conditions imposed on its use have not been met.

Limits to periods of residential accommodation that may be purchased

- 65 Regulations under section 17A of the Children Act 1989 limit the period of residential accommodation that may be purchased by means of a direct payment. A direct payment can not be made in relation to the provision of residential accommodation for a disabled child for a period in excess of 28 days, and in any period of 12 months for periods in excess of 120 days in total. The time limit is imposed to avoid inappropriate use of residential accommodation and reflects the time limits set out in the amended regulation 13 of the Arrangements for Placement of Children (General) Regulations 1991.

Ability to manage a direct payment

- 66 The council should only offer direct payments to people whom it considers will be able to manage them (alone or with assistance). Local councils have the discretion to refuse direct payments to anyone whom they judge would not be able to manage them. However, they should avoid fettering this discretion by making blanket assumptions that whole groups of people with parental responsibility for disabled children will be unable to manage a direct payment. Any such judgement should be arrived at on a case-by-case basis.

Consent to receiving a direct payment

- 67 The Act allows local councils to make direct payments only with the consent of the person concerned. While direct payments give people with parental responsibility for a disabled child greater control and independence, this increased freedom is inevitably accompanied by increased responsibilities. When people consent to direct payments, they take on responsibility for purchasing the services to which payments relate. This involves ensuring they receive the appropriate services to an acceptable quality, for example, ensuring they have in place appropriate arrangements to cover such emergencies as employee sickness.

Close relatives

- 68 Regulations prevent people with parental responsibility for a disabled child using direct payments to secure services from their partner (i.e. the other member of a married or unmarried couple). Nor may they secure services from a close relative living in the same household. A close relative in this context is a parent, parent-in-law, aunt, uncle, grandparent, son, daughter, son-in-law, daughter-in-law, step-son or daughter, brother, sister or the spouse or partner of any of these.
- 69 In addition, local councils should not allow people to use direct payments to secure services from a close relative living elsewhere or from someone else living in the same household as the direct payment recipient. This restriction is not intended to prevent people with parental responsibility for a disabled child from using their direct payments to employ a live-in personal assistant (provided that that person is not someone who would be excluded automatically by the regulations). The restriction applies where the relationship

between the two people is primarily personal rather than contractual, e.g. if the people concerned would be living together regardless of any employment relationship. A local council may decide that an exception to this general rule is justified, if it is satisfied that that is the most appropriate way of securing the relevant services.

“Charging” for direct payments

- 70 In considering whether, and if so how, to ask people with parental responsibility for a disabled child to make a financial contribution to the cost of their care package, local councils should treat people who receive direct payments as they would have treated them under the council’s charging policy if those people were receiving the equivalent services. In particular, in the case of a person with parental responsibility for a disabled child who is 16 or 17, or a person who is in receipt of income support, working families’ tax credit or disabled person’s tax credit under Part VII of the Social Security Contributions and Benefits Act 1992 or of an income-based job seeker’s allowance, the amount of the direct payment will be equal to the local council’s estimate of the reasonable cost of securing the provision of the service (subsection (6)). This effectively means that such people will not be required to make a contribution.

Transition to adulthood for the disabled child

- 71 Parents often face problems in supporting and preparing their children for an independent adult life. For people with parental responsibility for disabled children the issues around preparing their children for independence are more wide ranging than those facing 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 parts or all of the direct payment that has to date been managed by the person with parental responsibility. Where there is a difference of views between children and their parents over such matters provided that the children have sufficient understanding to make informed decisions the local council should give precedence to the views of the children. Fuller guidance on this can be found in the Carers and Disabled Children Act – Direct payments for young disabled people – Policy and practice guidance.

72 The Code of Practice on the Identification and Assessment of Special Educational Needs (SEN) requires Local Education Authorities to draw up a transitional plan for those with statements of SEN in partnership with the young person, his or her parents and other agencies including social services and health. The Code is being revised and under the revised version the headteacher will have formal responsibility for drawing up the plan. As the Connexions Service is rolled out, its personal advisors will need to be closely involved in this process. This transition plan which should, under current arrangements, be first considered after the child's fourteenth birthday (and during year 9 under the revised Code) is a key document relevant to health, social services, education, the developing Connexions Service and other agencies. It should inform decisions made about direct payments to disabled young people. For further information on the transition issues for people with parental responsibility for a disabled child see paragraph 29 of the Direct Payments Carers and Disabled Children Act – Direct payments for young disabled people – practice guidance.

Planning services in partnership with Parents and Children

- 73 Existing guidance emphasises the importance of:
- the family as the natural and most appropriate place for children;
 - local councils 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.

The Assessment Framework, paras 3.32 and volume 6 of the Children Act 1989 Guidance, para 6.1.

74 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 categories of 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 councils will wish to consider in partnership who is best placed to be responsible for management of part or all of the care package.
- 75 Whatever decisions are made when the disabled 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. However if they are going to continue in their caring role, such carers may be entitled to receive direct payments as an alternative to local council directly provided carers' services under the provisions of the Act. Carers' services would be provided or commissioned/funded to support the parent carer in their caring role and to help them maintain their own health and well being.
- 76 It will be important for local councils 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 para 71 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.
- 77 If the 18 year old cared for person is assessed as able to manage a direct payment (alone or with assistance) for any community care services they have been assessed as needing the payment may be made to a third party as agent for the user. It is for the direct payment recipient to choose who should act as their agent. The person to whom the direct payment relates (in this case the cared for person) must remain in control of the arrangements, and remain accountable for the way in which the direct payment is used. The 1996 Act does not allow social services departments to make payments to third parties to manage on behalf of the service user where the user is not in control. This is true even where the services provided as community care services are intended specifically to help the carer or parent carer. Fuller information may be found in the Community Care (Direct Payments) Act 1996 – Practice Guidance.

Further guidance on direct payments policy

- 78 Overarching guidance on matters relating to the 1996 Act may be found in The Community Care (Direct Payments) Act 1996 – Policy and Practice Guidance. This includes guidance on best value and monitoring. Guidance for recipients of direct payments includes a Guide to Receiving Direct Payments and an Easy Guide to Direct Payments. The former contains advice relating to employment.

Short Term Break Voucher Schemes

- 79 The Act provides for local council social services departments to run short term break voucher schemes. Short term break vouchers will enable parents to make arrangements for the additional support their disabled child will require while they take any breaks they have been assessed as needing. Short term break voucher schemes will offer flexibility in the timing of parents' breaks and choice in the way services are delivered to their children while they are taking a break.
- 80 Under the Act regulations are required to make provision for local councils to issue short term break vouchers. Regulations may, in particular provide for the value of a voucher to be expressed in terms of money or of the delivery of a service for a period of time, and for the person who supplies a service against a voucher, or for the arrangement under which it is supplied to be approved by the local council. Regulations may also provide for a maximum period during which a service can be provided against a voucher.
- 81 Fuller guidance on the development of local voucher schemes will be issued at the time such regulations are introduced.

Complaints

- 82 The Children Act 1989 requires all local councils 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 council has discharged its functions to the child under Part III of the Act - that is, local council 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 council foster parent; anyone else that the local council 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 Act the term “carer” includes people (age 16 and over) who may or may not be a relative and who may or may not be living with the person for whom they are caring.

The 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.

Children in need

The definition of children in need in the Children Act includes disabled children (section 17(10)). Section 17(11) 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”.

Fair Access to Care Services (FACs)

Guidance on fair access to care services, to be issued by the Department of Health in 2001, will provide a framework so that councils can determine eligibility for services in a fairer and more consistent way.

Framework for the Assessment of Children in Need and their Families

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.

Mental Health National Service Framework (MHNSF)

The MHNSF was published in September 1999. It focuses on the mental health needs of adults up to age 65. It sets standards in 5 areas: mental health promotion; primary care and access to services; effective services for people with severe mental illness; caring about carers; and preventing suicide.

National Service Framework for Older People

The forthcoming National Service Framework for Older People will, for the first time, set clear national standards defining the care and treatment that older people can expect.

Parental responsibility for a disabled child

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 “*The Children Act 1989 Guidance and Regulations Volume 1*”.

Principles of Part III of the Children Act

Terms used in section 6 of the 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. Therefore services provided under section 6 of this Act must safeguard and promote the welfare of the child.

Annex

Related policy initiatives

- 1 In considering this guidance local councils 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.

NHS Plan

Older People -Intermediate care and related services

- 2 The Plan provides an extra £900 million by 2003/04 for investment in intermediate care and related services to promote independence and improved quality of care for older people so as to:
 - promote independence through active recovery and rehabilitation services with an extra 5,000 intermediate care beds and a further 1,700 supported intermediate care places, together benefiting around 150,000 more older people each year
 - prevent unnecessary admission to hospital with extra rapid response teams and other forms of admission prevention benefiting around 70,000 more people each year
 - enable 50,000 more people to live independently at home through additional home care and other support. In addition, 50% more people will benefit from community equipment services (assistive technology) ranging from simple care equipment and adaptations, like grab rails and pressure relief mattresses, to more sophisticated equipment such as fall alarms and remote sensor devices
 - extend short term break services for carers so that they benefit a further 75,000 carers and those they care for. (by 2003/4)

Mental Health

- 3 The Mental Health National Service Framework set a specific standard 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 takes this further by specifying investment in carers' support (and indeed new services for women). Further work will include a focus on black and minority ethnic service-users, recognising the discrete needs of them and their families.

Children

- 4 The NHS Plan also makes major commitments to tackle child health inequalities and includes a planning milestone for the provision of support services to an additional 6,000 disabled children by April 2002.

Quality Protects

- 5 The Quality Protects programme requires local councils each year to complete a Management Action Plan setting out how they are improving their services to disabled children and their families and making progress towards achieving all the children's services objectives. The Quality Protects programme has now been extended to 2003/2004 and backed by additional resources from the children's services grant. From April 2001 disabled children have been included in the priority areas for the grant. £60 million has been earmarked for disabled children and their families - £15 million in 2001/2002 and 2002/2003 and £30 million in 2003/2004. This additional funding will:
 - increase provision of a wider range of flexible family support services including short term breaks;
 - help integrate disabled children into mainstream leisure and out of school services;
 - provide more and better information for families and increase the availability of key workers and other measures to improve co-ordination.

Implementation of Health Act 1999 – Partnership Arrangement

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

Quality and Choice – A Strategic Framework for housing older people

- 7 A strategic framework for housing for older people jointly published by the Department of Health and the Department of Environment Transport and the Regions in January 2001 considers a range of housing options for older people to enhance their quality and choice. It also promotes greater linkage between housing, social care and health policies to encourage new solutions to promote independence.

Education

- 8 Support should be provided to disabled or ill parents so that young carers do not assume levels of caring responsibilities which 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 DfEE 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.

Fair Access to Care Services

- 9 The Department of Health will issue statutory guidance on Fair Access to Social Care Services during 2001. The guidance will provide a common framework for determining eligibility for adult social care services, provided or purchased by councils with social services responsibilities. It will also provide guidance on procedures for reviewing adult service users' needs and continuing eligibility for support. Implementation by councils should lead to fairer access across the country and the provision of support to promote independence.

General Principles of Assessment

- 10 Both the National Service Frameworks (for Mental Health and Older People) cover assessment and related aspects of care management. As part of the package of guidance relating to the Carers and Disabled Children Act 2000 there is a Practitioner's Guide to Carers Assessments'. To ensure there is a consistent and contemporary approach to assessment across all adult user groups, the Department of Health also intends to issue a set of General Principles of Assessment that councils can use when assessing the needs of other user groups.
- 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* remains the main source of guidance for local councils.

National Service Framework for Older people (NSFOP)

- 12 The forthcoming NSFOP will, for the first time, set clear national standards defining the care and treatment that older people can expect.

Learning Disability White Paper

- 13 The Government intends to publish a White Paper on services for people with learning disabilities and their families Spring 2001. It will contain important issues for consideration when looking at the needs of carers of people in this client group.

