

CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Policy Briefing

Carers and Disabled Children Act 2000 Policy and Practice Guidance

Briefing for Carers' Groups and Carers' Organisations

The Guidance on the C&DC Act is made up of four publications:

- * policy guidance
- * practice guidance
- * practitioner's guide to carers' assessments
- * policy and practice guidance on direct payments for young disabled people

Out with the old and in with the new?

Just because the Carers and Disabled Children Act 2000 (C&DC Act) has been brought in, it does not mean that the Carers (Recognition and Services) Act 1995 (C&RS Act) is no longer relevant. In fact, the situation is quite the reverse. The C&DC Act introduces new provisions, but the C(R&S) Act is still extremely important in ensuring that a carer's "ability to care" is assessed and that the people they care for receive additional help on the basis of that assessment. Carers UK would recommend that local councils look to assessing carers under both the C&DC Act and the CR&S Act.

Summary of the main provisions of the C&DC Act

From 1 April 2001 in England, the following provisions have come into force:

- * a right for a carer to request an assessment of their needs, even when the disabled person refuses an assessment. The carer has to be aged over 16 and has to be providing or intending to provide regular and substantial care for someone aged over 18.
- * a right for parents of children with disabilities to request an assessment
- * the power for local authorities to provide carers with services which help them to care
- * the ability for local authorities to provide direct payments i.e. cash instead of care) to parent carers, carers for their own services and young disabled people aged 16 or 17
- * the ability for local authorities to charge carers for their own services

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CARERS UK

The final provision of the Act, which will come into force later in the year is:

- * vouchers for breaks services

Accompanying leaflet

The Department of Health has also produced a basic leaflet designed to raise awareness of the changes. Entitled "How to get help in looking after someone, a carer's guide to a carer's assessment", the Department is advising local councils to ensure carers are given a copy when the user is being assessed.

Purpose of an assessment

The practice guidance states that a carer's assessment is carried out at the request of the carer in order:

- * to determine whether the carer is eligible for support
- * to determine the support needs of the carer i.e. what will help them
- * to see if those needs can be met by social or other services.

Local authorities also have a duty to respond to a request from a carer for an assessment. In other words they must assess the carer if they provide or intend to provide regular and substantial care for someone for whom the local authority may provide community care services. Carers UK has received examples of where local authorities have refused assessments or have delayed the assessment for an unreasonable amount of time, against Government Guidance and the law.

Section 1, the right to request an assessment

Carers have a right to request an assessment if the person they are caring for is someone for whom the local authority may provide community care services. Although by law it is up to the carer to request an assessment, the practice guidance states that it is good practice for local authorities to offer an assessment. Carers UK recommends that local authorities have a written policy of offering assessments to carers.

The legislation means that, even if the disabled person refuses an assessment or services, the carer can still have an assessment of their own needs. To establish whether the disabled person is someone social services might provide services for, the policy guidance states that local authorities can get information from GPs (para.13, policy guidance). They can also take referrals from carers' organisations and the practice guidance has a good sample referral form (page 9).

Younger carers aged 16 and 17

The guidance states that only in exceptional circumstances would the child over

16 be assessed under the Carers and Disabled Children Act 2000 (para 13, practitioner's guide). Normally, they would have an assessment under the Children Act 1989. Whatever law is selected, the assessment should be child focused. Where an assessment of a young carer takes place under this Act, the guidance states that assessments should ensure that younger carers aged 16 or 17 do not take on inappropriate levels of caring. "Local councils should ensure that such young people's futures are not adversely affected by caring responsibilities" (para 20, policy guidance).

Regular and substantial care

A carer has to be providing or intending to provide regular and substantial care in order to be able to request an assessment. This term is not defined, but the policy guidance states that it should be based on two areas:

- * key factors relevant to sustaining the caring role
- * the extent of risk to the sustainability of that role (see risk section below)

In research carried out in 1997 on the implementation of the Carers (Recognition and Services) Act 1995, Carers found that local authorities defined "regular and substantial care" in many ways. We would recommend that a simple hours limit is not used because caring impacts on people in very different ways.

The policy and practice guidance both state that intermittent caring for someone with mental illness can count as regular and substantial care. Carers UK recommends that local authorities review their policies and procedures to ensure that carers of people with mental illness are not excluded from definitions of regular and substantial care.

Section 6: Parent carers' rights to an assessment

The Act also contains a section on parent carers, reiterating most of the provisions of the Carers (Recognition and Services) Act 1995 but with one main difference. The Carers Act 1995 entitles a parent carer to an assessment of their "ability to care" when the local authority is assessing the needs of their child under Part III of the Children Act 1989 or s. 2 of the Chronically Sick and Disabled Persons Act 1970. This new legislation (C&DC Act) entitles the parent to an assessment of their "ability to care" if the local authority is satisfied that they might provide services to the child or the family under s. 17 of the Children Act. This essentially means that a parent carer can ask for an assessment at any point in time. This is important because Carers UK has cases of carers who have been refused an assessment of their needs on the basis that the disabled child had already been assessed.

Section 2: Services for carers

The local authority must consider the assessment of the carer and decide:

- * whether the carer has needs in relation to the care s/he provides
- * whether they could meet these needs with services
- * whether they are going to provide those services.

They then have to decide:

- * would the service help the carer to care?
- * would the service help to maintain the carer's health and well-being?

What are carers' services?

Because there is no definition of carers' services, it could, potentially, be anything. The practice guidance encourages local authority staff to think creatively and flexibly. Examples given so far include washing machines, a holiday, driving lessons, telephones but it could also encompass equipment and more suitable housing for the carer.

In some circumstances, a carer's service could also be a community care service which is actually "delivered" to the disabled person. These services could include sitting services. However, in this situation, these services can only become the carers' service if both the disabled person and the carer agree. This agreement is important because it ensures that carers and disabled people decide what is best for them, rather than a professional making an arbitrary decision. The legislation strictly forbids carers' services involving any intimate care of the disabled person.

The practice guidance states that local authorities should review their decisions not to provide shopping, housework, cleaning or other low level services.

Information about carers' services

Practice guidance states that local authorities should aim to produce and publish an A to Z of local carers services and other forms of carers support (page 11, para 31). It goes on to state, "councils will want to ensure that carers are fully informed of the current availability of free community based services in the voluntary sector."

What are intimate care services?

Regulations define these services as lifting, washing, grooming, feeding, dressing, bathing, toileting, administering medicines or otherwise having physical contact with the person being cared for. It also states that anyone providing assistance with these functions, including supervising dressing, bathing or using the toilet could be deemed "intimate". The policy goes on to suggest that even asking the disabled person a question about their relationship with others might be considered embarrassing or intrusive. The guidance does not state that this would necessarily contravene the law, but it draws the definition of "intimate" very broadly. Carers UK would recommend that local councils draw up protocols which service providers endorse in order to ensure that there is clear understanding about what sorts of services might be intimate and what not.

There are situations when carers' services can involve intimate contact with the disabled person. The regulations state that this would be:

- * during the delivery of the service, if the disabled person asks for certain

help e.g. assistance in going to the toilet or assistance in having a mid-morning cup of tea.

- * if the disabled person is in situation in which they might suffer serious personal harm.

Carers UK has emphasised throughout the passage of the Act, that carers will not use a service unless they are satisfied that the person they care for will be safe and well looked after. This is why we believe it is vitally important to develop clear protocols. The practice guide uses several good examples on pages 35, 36 and 37 to illustrate these points.

Section 4: Deciding who the services belong to

The Act could make things very confusing, particularly for users and carers, about who "owns" the service. This is important because it affects who pays as well as who has the right to complain, etc. There are some simple steps that could be taken to decide which services are the carers and which belong to the disabled person:

1. Services which can only be the disabled person's, particularly if they are intimate care services.
2. Services which can only be the carer's service e.g. a holiday on their own
3. Services which would normally belong to the disabled person (a community care service) but which could become a carer's service. Agreement is needed from both the disabled person and the carer for this to happen. There is potential for confusion here.
4. When deciding whose service is whose, the local authority staff must not take into account the financial position of either party. This is set down very clearly in the Act. Local authorities must do the needs assessment first, make service decisions second and then carry out a financial assessment.
5. Local councils must record, on the assessment, who "owns" which service, the carer or the disabled person. This should also be reflected in the care plan. Carers UK would recommend that local authorities develop clear assessment forms which allow good recording. An inspection by the Social Services Inspectorate found case recording of carers' assessments and carers' needs to be quite poor. This will clearly need to change in the light of the new legislation.
6. Carers should be given a copy of their care plan.
7. Carers should also be given information about how to complain.

Section 8: Charging

The Carers and Disabled Children Act gives councils the power to charge carers for their own services in the same way that disabled people are charged for their services. Carers UK fought unsuccessfully for this provision to be abolished and continues to press Government to change their policy on this area. Local councils should be consulting local carers groups about the changes they will make to their charging regime. Carers UK has recommended the following:

- * local authorities should use their discretion not to charge carers for their own services. These services are designed to improve their health and wellbeing and it would be counter-productive to charge carers for them.
- * local authorities should not charge for services which give carers a break.

If they charge, local authorities should ensure that:

- * they take account of the cumulative impact of charging both the carer and the disabled person
- * they account for the impact of charging on the health and well-being of the carer and disabled person
- * carers in receipt of Income Support are not charged
- * Invalid Care Allowance is not counted as income when a financial assessment is being undertaken
- * the costs of caring are taken into account when deciding what charges would be "reasonable". These costs might include increased transport costs for example.
- * partners and spouses income should not be part of any financial assessment.

The policy guidance states that, "carers may not be charged for community care services provided to the people they care for." Given that this guidance is issued under s. 7(1) of the Local Authority Social Services Act 1970, this statement has, in effect, the force of law. This reinforces Carers UK's interpretation of the law that spouses' incomes should not be taken into account during a financial assessment of a disabled person. This guidance has greater legal weight than the confusing and conflicting paragraph 19 of the Advice Note published by the SSI in 1994. This suggested that, in individual cases, local authorities could consider whether the disabled person had reliable access to their spouses or unmarried partners' income. In other words, the Carers and Disabled Children Act guidance on charging could be said to "supercede" the Advice Note.

It is not possible for local authorities to charge for services provided under s. 117 of the Mental Health Act 1983. These are after-care services once a person who has been detained under the Act, is discharged from hospital.

The practice guidance also states, "once someone has been assessed as needing

a service that service should not be withdrawn because the user or carer refuses to pay a charge.”

In terms of process, the practitioner’s guide makes it quite clear that a financial assessment is completely separate from the Carers and Disabled Children Act assessment. However, it also states that it is important that charges and financial assessment are clearly explained to both the carer and the cared for person as part of the assessment process.

Sections 5 & 7: Direct payments

Local authorities now have the power to provide direct payments to:

- * parents of disabled children for Children Act services
- * carers for their own services (s. 2 services)
- * young disabled people aged 16 and 17

In all instances, direct payments cannot be used to pay a close relative, spouse or partner, or someone else living in the household. Although local authorities do not have to run direct payments schemes by law, they cannot “unreasonably” refuse a request to have direct payments. The Health and Social Care Bill currently passing through Parliament would ensure that if an eligible person asked for a direct payment, the local authority would have a duty to provide them. The Bill may or may not become law depending on the election timing.

Direct payments can be difficult to understand and Carers UK will be producing a booklet on direct payments for carers. This will be published later in the year. In the meantime, the CarersLine can advise carers on about what is involved in managing a direct payment and how to get one. Carers UK would be keen to hear from any carers who have a direct payment in order to learn from their experiences (see end of the briefing).

The policy and practice guidance makes it very clear that good information and support networks need to be set up for anyone thinking about or managing a direct payment. The guidance focuses, in particular, on the appropriateness of direct payments for a young carer aged 16/17.

Direct payments could be particularly valuable for parents with a child with complex needs or for carers from ethnic minorities who do not find the local authorities’ support suitable and would prefer support from their own community. It could also help families be more flexible in supporting people with mental illness for example.

There are particular issues for parents of disabled children and disabled young people which are set out below.

Section 7: Direct payments and parent carers

All parents of, or people with parental responsibility for, disabled children who have been assessed for Children Act support will be eligible for direct payments for those services. The guidance places a great deal of emphasis on local councils ensuring that parents take a number of steps to satisfy themselves they employ a "suitable person" for their child. The guidance expects local authorities to alert parents to the risks of abuse and expects them to provide parents with good advice to minimise those risks.

A parent considering employing a person with a direct payment can ask the local authority to carry out a criminal record check on the person. The local authority has a duty to comply with the parent's request.

If someone wants to be employed to care for a disabled child, they have to make an application for a background check to be carried out. The application is counter-signed by the council and the individual has to pay a fee for each background check. It is not the parent who pays but the person who is going to be employed. The practice guidance suggests that local authorities should increase the parents' amount of direct payments so that they can reimburse the employee's costs of getting the background check done. Carers UK welcomes this statement because it can be difficult to find appropriate support for disabled children without the added barriers of extra costs that the employee would have to bear.

Local authorities cannot force parents to have a direct payment if they do not want them. Throughout the passage of the Carers and Disabled Children Act we emphasised that councils should always give carers a choice.

Once the child reaches 18

When the child reaches 18, if they do not have the ability to manage a direct payment, then the parent cannot continue to receive the direct payments for services on their behalf. Carers UK foresees that, for a family who has had the flexibility of employing their own staff to care and support their child, the transition could be extremely difficult. Carers UK would recommend that local authorities seek to help parents maintain maximum flexibility with care arrangements so that the transition is smooth for the young disabled person as well as for the family. The guidance states that local authorities should "ensure that the impact of the loss of a direct payment option is minimised and that as far as possible continuity in service delivery is achieved."

Parents who receive Income Support, Working Family Tax Credit, Disabled Person's Tax Credit or income based Job Seekers Allowance should not be financially assessed for direct payments.

Section 7: Direct payments for disabled young people aged 16/17

When the disabled child reaches 16, they are able to have direct payments for some or, potentially all, of their services. As with all direct payments, the young

person has to be willing and able to manage the direct payments, with assistance if necessary. The 16/17 year old can only receive direct payments for services they have been assessed as needing, not the services designed to support other members of the family.

The only contracts which are binding on minors (i.e. people under 18) are those for "necessaries". The policy guidance suggests that this would include any services identified by the assessment and bought with a direct payment. The 16/17 year old would have the same employer responsibilities as any other direct payment holder e.g. holiday pay, emergency cover arrangements, etc. They also have a responsibility to ensure that they receive services of an appropriate quality.

The policy guidance emphasises that local authorities' decisions have to be made on a case by case basis. They cannot make blanket assumptions about individuals ability (or not) to manage a direct payment. It states that councils' overriding requirement is to ensure that the direct payment (if appropriate) would promote and safeguard the welfare of the young person.

In making decisions about direct payments, the policy guidance directs local authorities to balance the wishes of the parent with the wishes of the child. It emphasises that services under the Children Act are intended to assist the parent and enhance, not undermine, the parent's authority and control. These are important issues if conflict arises between parent and child, and if the parent is concerned for the safety and welfare of their child.

The direct payment could cover part or all of the service package. The process for criminal record checks is the same as for parents managing a direct payment. Charging or contributions arrangements towards direct payments are not recoverable from a young person in receipt of Income Support, working families tax credit, disabled persons tax credit or income based job seekers allowance.

Sections 3 & 7 Short term break vouchers schemes

This section is not being implemented until later in the year and there is no guidance yet. The Act gives local authorities the power to provide disabled people or parents of disabled children with vouchers for services which would give carers a break. Those vouchers could be expressed in cash or hours value terms. Although guidance is being published later in the year (this section is not yet in force), the policy statement on the Carers Grant 2001/2002 states that part of the funding could be used in setting up voucher schemes. Local authorities are already setting up voucher schemes ahead of the implementation of the law.

Research on voucher schemes commissioned by Carers UK recommended that:

- * local authorities build the scheme in partnership and consultation with carers
- * the range of breaks available are sufficiently varied to give carers a choice
- * carers need good quality information from local authorities about how vouchers work.

Funding to implement the Act

Throughout the passage of the legislation, Carers UK urged Government to put funding behind the Act. Unfortunately, we have not been successful and the Association of Directors of Social Services is concerned about councils' ability to implement the Act without additional financial support. Government, however, believes that funding for services under the Act should come out of existing local authority funding. Carers UK believes that a future Government should address this issue immediately. If local groups wish to take action, they could consider writing directly to the Minister of State for Health, John Hutton MP, Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS. You could also consider writing a joint letter with other local organisations and the director of social services.

In the meantime, a proportion of Carers Grant monies – up to 10% - can be spent on developing carers services. However, these services can only be used for carers where the cared for person has refused all help. This is to ensure that the main focus of the Carers Grant remains providing breaks for carers. See CNA's briefing on Year 3 of the Carers Grant.

Role of Health Services, Housing and Education

Because the legislation covers carers who provide or "intend to provide" care, it is essential that the health service is included in discussions about the implementation of the Act. In particular, hospital discharge policies and procedures need to ensure that carers are offered an assessment. The practice guidance states that, "health staff have a key role in helping carers access the support they need".

For the first time, guidance has referred to housing. It states that, "in planning services for carers, councils with social services responsibilities need to involve housing authorities and other housing professionals to ensure that the housing needs of cared for people have been properly addressed." (para 7) It is vital that policies on the Act refer to housing needs.

The practice guidance (Para 8) states that the role of education is important for young carers and disabled children.

Relationships with other key agencies

The practice guidance lists a whole series of agencies with whom the Act would need to be implemented. As well as Health Authorities, Trusts, Primary Care

Trusts, etc. is also includes the Employment Services, Skills and Training Councils, Local Education Authorities, Housing Authorities, Connexions Services as well as carers, young carers and disabled people's organisations.

PRACTICE ISSUES FOR CARERS ASSESSMENTS

Assessments of parent carers comes under different guidance called, Framework for the Assessment of Children in Need and their Families.

New issues about assessments

The practice guidance addresses a number of new issues in policy terms which local authorities' policies will have to address. These include:

- * employment issues for carers
- * a new concept of risk for carers
- * more than one carer in a relationship could be assessed
- * the assessment should count the inconvenience of caring at a distance
- * caring across local authority boundaries – it is the local authority where the disabled or elderly person lives that has the responsibility for the carer's assessment.

Key points about the assessment in practice guidance

It should:

- * focus on the outcomes the carer wants to see (Appendix 1, practitioner's guide contains a list of outcomes including a good nights sleep, etc.)
- * be a carer centred process
- * look at the impact of the whole caring situation
- * consider the level of choice a carer has in undertaking caring tasks
- * consider health and safety issues for the carer
- * look at what support carers might need to manage daily routines e.g. help with housework
- * look at what opportunities the carer has to maintain social contact, employment, etc.

The practitioner's guide suggests various areas that the assessment could cover including:

- * the carer's role
- * breaks and the carer's social life
- * their physical well-being and personal safety
- * care of the home/s
- * accommodation
- * finances
- * employment and work
- * education and training

- * current practical and emotional support
- * wider responsibilities i.e. parenting
- * future caring role
- * emergency planning
- * access to information and advocacy
- * agreed outcomes
- * complaints and challenges
- * reviews of the assessment
- * charging

Carers and employment

The practice guidance states, “carers should be support to stay in work or return to work where this is what they want to do”. The practice guidance directs councils to:

- * identify links with training agencies
- * ensure the Welfare to Work Joint Investment Plan addresses carers’ employment issues
- * audit services to see how well they support carers who wish to work or return to work
- * consider in assessment whether a carer is at risk of giving up work
- * identify how well appointments and multi-agency assessments accommodate working carers
- * evaluate how well supported the local authority’s own employees who are carers are by employment policies
- * actively promote their flexible working policies to all staff.

Levels of risk

The practice guidance sets out four levels of risk extending from critical risk to low risk on pages 26 and 27. If a carer is at critical risk then this might be because:

- * their life might be threatened
- * major health problems have developed or will develop
- * the carer has an extensive loss of choice about what tasks they have to perform
- * their employment is at risk
- * and their relationships are at risk.

Other practice issues:

- * carers still have to request an assessment but the practitioners’ guide restates Department of Health policy that it is good practice to offer an assessment.
- * carers should be informed of the complaints procedures run by the local authority when they are being assessed.
- * Carers must always receive a copy of their assessment include a

- statement of their needs (practitioner’s guide, para 54).
- * local authorities should ensure that information is provided in languages and formats appropriate for their different local communities.
- * carers should be told of their right to have a friend or advocate present if they wish to during the assessment (para 60)
- * carers should be given information about community services such as carers groups and other support groups (para 52).

The practice guidance suggests a range of action that local authorities should be taking:

- * publication of an A to Z of carers services and carers’ support
- * clear and published eligibility criteria for carers’ assessments (para 38)
- * action to ensure their staff are culturally competent or can access the relevant expertise to ensure that carers from black and ethnic minority communities are not disadvantaged (para 39)
- * surveys to identify carers’ satisfaction with the assessment process (para 40)

Who can undertake assessments?

The practice guidance suggests that staff other than local authority staff could carry out carers’ assessments, such as a district nurse. It states that there has to be an agreement between the local authority and the other statutory body undertaking the assessments. Carers UK would emphasise the need for training for these staff. The practice guidance also notes that it is not possible for a local authority to delegate its assessment responsibilities to a voluntary organisation.

Sharing knowledge

Carers UK is often asked about best practice and about what is happening in different parts of the country. Your feedback to us not only facilitates this process, it also highlights issues that we may need to feed into Government. Please provide feedback on the following by e-mail to policy@ukcarers.org or emily@ukcarers.org or by letter to Emily Holzhausen, Public Affairs Manager at Carers UK.

In particular, we are interested in:

- * local authorities designing direct payments schemes
- * local authorities reviewing their employment policies
- * carers’ experiences of assessments
- * carers’ experiences of direct payments, including parent carers
- * carers issues about charging for services

Useful publications:

Carers and people with parental responsibility for disabled children, Policy Guidance, Carers and Disabled Children Act 2000 Department of Health, March 2001. Ref: 23397

Carers and people with parental responsibility for disabled children, Practice Guidance, Carers and Disabled Children Act 2000 Department of Health, March 2001. Ref: 23398

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 Department of Health, March 2001. Ref: 23399.

Direct Payments for young disabled people, Policy Guidance and Practice Guidance, Carers and Disabled Children Act 2000 Department of Health, March 2001. Ref: 23340.

Copies of the **Carers and Disabled Children Act 2000** are available from The Stationery Office Ltd, PO Box 29, Norwich NR3 1GN. Tel: 0870 600 5522 or through the internet at www.ukstate.com

Single copies of the **Carers (Recognition and Services) Act 1995** can be obtained either from Carers UK free of charge, or from the Stationery Office for which there would be a small charge.

Framework for the Assessment of Children in Need and their Families

Department of Health, Department for Education and Employment, Home Office, published by The Stationery Office (see above) or on the internet at: www.open.gov.uk/doh/quality.htm or www.the-stationery-office.co.uk/doh/facn/facn.htm

The Department of Health and copies of the free leaflet, **How do I get help?**, are available free from: Department of Health publications, PO Box 777, London SE1 6XH. Fax: 01623 724524. E-mail: doh@prolog.uk.com. Please use the reference numbers above when ordering. All publications are also accessible at the Department of Health's website: www.carers.gov.uk.

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