

Implementing the Carers (Equal Opportunities) Act 2004



SCIE's aim is to improve the experience of people who use social care services, by developing and promoting knowledge about good practice in social care. We pull together knowledge from diverse sources through working with a broad range of people and organisations. We share this knowledge freely, supporting those working in social care and empowering service users.

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Introduction

SCIE aims to improve the experience of people who use social care by developing and promoting knowledge about good practice. Using knowledge gathered from diverse sources and a broad range of people and organisations, we develop resources that we share freely, supporting those working in social care and empowering service users.

At the request of the Department of Health, we have produced this practice guide to the 2004 Act. It is easy to use and translates what is known from research and policy into recommendations for practice (practice points) and gives examples (ideas from practice). The guide is designed to answer any questions on the implementation of the Act, as well as provide food for thought.

Working with you

SCIE welcomes email or written comments on any aspect of this guide. The feedback will inform future practice guide updates. We are also keen to collect examples that translate key research findings and practice points into practice. You can contact SCIE at www.scie.org.uk.

About this guide

As a result of community care legislation, and because people are living longer, the number of those needing care in the community has increased. This has led to more people taking on unpaid caring responsibilities - almost six million people in the UK now care for a relative, friend or neighbour in need of support.

Carers' and 'care workers'

The word 'carer' refers to people who provide unpaid care to a relative, friend or neighbour who is in need of support because of mental or physical illness, old age or disability. It does not include people who work as volunteers or paid carers; these people should be referred to as 'care workers'.

It is also important to remember that some people who use social services are also 'carers'. For example, many people with learning disabilities provide support to their ageing parents.

The government has increasingly recognised the contribution that carers make to society and has passed legislation that acknowledges their needs and entitles them to assessment and services in their own right^(1,2). The Carers (Equal Opportunities) Act 2004 seeks to ensure that:

- carers are identified and informed of their rights
- their needs for education, training, employment and leisure are taken into consideration

- public bodies recognise and support them.

The Act is an acknowledgement that carers are entitled to the same life chances as others and should not be socially excluded as a result of their caring role. Responsibilities for supporting carers need to be agreed across organisational boundaries to ensure that carers are recognised and supported by the whole of society and not just by social services.

The Act applies - in England and Wales only - to:

- carers who provide or intend to provide a substantial amount of care on a regular basis for another individual aged over 18
- people with parental responsibility for a disabled child, who provide or intend to provide a substantial amount of care on a regular basis for that child(3).

Local authorities will face different challenges in implementing the Act, depending on the complexity of local statutory and non-statutory networks, the demographic characteristics of the local population and geographical considerations. Planning on a local level is essential to ensure that such factors are taken into consideration and local needs are properly met.

Since the 2004 Act the White Paper, *Our health, our care, our say* (2006) has promised further commitments in the 'new deal' for carers. This includes:

- a new strategy for carers which is expected in early 2008
- the establishment of an information/ helpline for carers
- short-term, home-based support is for carers in crisis or emergency situations an Expert Carers Programme. (similar to the Expert Patients Programme) to provide training for carers to develop the skills they need to take greater control over their own health, and the health of those in their care.

Who the guide is for

This guide is designed primarily for the social care managers and practitioners responsible for the implementation of the Carers (Equal Opportunities) Act 2004. The essential steps and many of the practice points throughout the guide will be useful to those responsible for strategic planning and commissioning. Practitioners will need the support of senior and line managers and an appropriate framework to enable them to help carers.

The guide may also be useful for carers, people who use social services and professionals from other organisations that support carers. Carers are increasingly being acknowledged in new legislation and guidance, for example, The Delayed Discharges (Continuing Care) Directions 2004 and the Mental Capacity Act 2005. This

guide also aims to assist other authorities (e.g. housing, education and health) in developing their methods for acknowledging, including and supporting carers.

Aim of the guide

The purpose of this guide is to offer quick and easy access to information that will aid the implementation of the 2004 Act alongside previous related legislation.

The guidance format is designed to enable strategic planners, managers, practitioners, carers and public authorities to think creatively about the implementation of the Act. The guide does this by:

- addressing practice issues relating to the implementation of the Act
- summarising the policy context and key research and policy findings
- providing references
- providing practice points
- giving examples from practice
- referring to relevant legislation, guidance and standards
- providing further information and useful web links.

What the guide does not cover

The guide focuses on the implementation of the Carers (Equal Opportunities) Act 2004, and includes areas of practice not specific to the Act that are thought to be useful. It does not replace any previous guidance but makes reference to it where appropriate and should be used alongside it.

Previous legislation has been accompanied by policy and practice guidance, which remains in place and is available on the Department of Health website. In addition, the law and standards are comprehensively covered in *Carers and their rights: The law relating to carers* (PDF) (4), produced by Luke Clements, in conjunction with Action for Carers and Employment National (ACE) and Carers UK. This gives an overview of the relevant legislation and guidance and is helpful in bringing together the various strands under a number of themes.

Essential steps

Introduction

Many of the recommendations in this guide rely on a framework for implementation. The following essential steps, which have emerged as necessary to facilitate implementation, would need to be addressed at a strategic level within local authorities. They are not required by the Act but would form the basis of a model of good practice.

Participation

Carers should participate at all levels in local arrangements, including planning, implementation, service development, recruitment, training and evaluation. The development of participation, as opposed to consultation or involvement, is still in its infancy and there is much debate about the value of current approaches⁽⁵⁾. SCIE has published a position paper of carer participation. The paper aims to identify what is happening in the social care sector with the involvement of carers and the impact participation has had on service improvement.

For any strategy to be effective, carers must agree with the method of implementation. Good practice includes:

- ensuring that carers are supported to participate (e.g. through training, peer support, preparation for meetings)
- having meetings at times that are convenient to carers
- providing appropriate replacement support to the cared-for person
- providing (or funding) transport to meetings
- ensuring that material is accessible and understandable
- avoiding the use of jargon and acronyms
- allowing carers to opt in and out of participation in line with the demands on them as carers
- agency staff attendance at carers' meetings **(6)**
- ensuring that more than one carer is involved in meetings, to provide moral support **(6)**
- support from a staff mentor **(6)**
- making information available about staff members and other attendees at meetings **(6)**
- paying carers for their work.

A number of organisations, both local and national, are now paying carers for their work, either by the day or at an hourly rate for attendance at meetings. When making payments, organisations should ensure that carers have specialist advice to help them assess the impact of any income on their benefits. In Sunderland, for instance, some carers have raised concerns about this issue and prefer subsistence payments, reimbursement for travel and funding for replacement care.

In Wigan, carers participate in two panels to decide on grant payments. One is for 'one-off payments' and consists of three representatives from adult services, one representative from the voluntary sector and two independent carers. The second panel is to allocate money to local voluntary groups that support carers. This consists of up to 10 independent carers, representatives from services for adults and children. A grant panel training session is provided for the carers involved.

Social services lead on carers' issues

It is important that each social services department has a named person with responsibility for taking forward the implementation of the Act in conjunction with previous legislation relating to carers. In the recent White Paper, *Our health, our care, our say* (REF) the Government made a commitment to encourage councils and PCTs to nominate leads for carers' services. Some authorities, such as Swindon, already have carer's leads in place in PCTs and acute trusts.

The Carers' lead post should facilitate the implementation of the Act across boundaries, organisations and services for children and adults. It does not remove the responsibility of other workers to address the needs of carers, but should offer leadership and a coordinated approach to carers' issues.

The role of the carers' lead comprises:

- liaising with other public bodies (local authorities, education, children's services, housing and health)
- being aware of the responsibilities of other public bodies towards carers
- ensuring that other public bodies are aware of the requirement for 'due consideration' to be given to local authority requests for help in supporting carers (for example, by circulating a letter to the heads of organisations)
- engaging with local organisations and non-statutory agencies (e.g. voluntary organisations and carers' groups, leisure facilities, local shops and businesses)
- engaging with local employers to raise awareness about carers' issues and promote the 'business case' for employing carers
- working with local community groups to develop services to meet local needs
- promoting the participation of carers at all levels including planning, implementation, service development, recruitment, training and evaluation
- identifying and addressing the support needs of participant carers
- identifying sources of funding to support carers' services

- ensuring that the quality of support to carers is evaluated.

Clear published eligibility criteria

The local authority is responsible for determining eligibility for services. All other agencies, as well as carers themselves, need to have access to this information.

Services to carers are discretionary. Although a carer's assessment uses the same grading system as the Department of Health's 'fair access to care services' (FACS) - i.e. 'critical', 'substantial', 'moderate', 'low' (7) - to assess risk to the sustainability of the caring role(2), there is no duty to provide services to carers(4). However, 'identification of a critical risk in a Carers' Act assessment triggers a local authority obligation to make an appropriate response to address this risk'(4).

A practitioner's guide to carers' assessments (8) suggests a list of key questions to ask when assessing the sustainability of the caring role.

The FACS guidance (7) states that disabled parents should be supported in their parenting role and that this may be beneficial for children, some of whom are young carers. Supporting disabled parents is the responsibility of adult services.

Clements (4) (pp 37 – 38 or point 4.63 – 4.67) provides a full explanation of the application of eligibility criteria in carers' assessment.

In Wales, a person's needs are assessed from the point of first contact under the Unified Assessment Process. It is also mandatory to include a carer's assessment as part of every community care assessment. The guidance integrates FACS and an adapted version of the English Single Assessment Process.

Multi-agency strategy

As part of the implementation of the Act, each locality should have a multi-agency strategy for carers. This should be agreed by the relevant agencies, including health, housing, education, carers' groups, leisure facilities, Jobcentre Plus and local employers. The strategy should include planning for staff awareness training, the development of an information strategy and methods for monitoring the impact of the various aspects of implementation.

Joint working between adults' and children's services

There are many situations where both adults' and children's services will be involved in supporting people who are either caring for or receiving care from family members. A holistic, family approach is essential to providing a seamless service to carers.

Local profiling

Each locality needs to have information about the local population and local needs. The

information should be based on available data (e.g. from the Census) and on consultation with local people.

Joint commissioning

Arrangements for the joint commissioning and funding of projects need to be in place.

A self-assessment tool, available on the Improvement and Development Agency website, will assist councils in determining how well they are supporting local carers. In addition, the King's Fund has published a guide - *How good is your service to carers? (10)* - to aid the evaluation of quality standards for local providers of carer support services.

Section 1: Duty to inform carers of the right to assessment

The Act places a new duty on local authorities to ensure that carers are informed of their right to an assessment. The local authority must make an effort to seek out carers who are not known to social services (commonly known as 'hidden carers'), and must ensure that information is available and accessible for all carers.

A section on young carers has been included in this guide. Although children should not be undertaking regular and substantial caring responsibilities, it is widely acknowledged that some still do. This guide seeks to clarify responsibilities towards this group.

Providing information

Key research and policy findings

- Information needs to be provided in a more systematic way.
- The impact of information strategies needs to be assessed.

Practice points

- Through the multi-agency strategy, develop an information strategy.
- Ensure that a named person in each authority is responsible for carers' information.
- Ensure that information is free of jargon and in a variety of formats.
- Ensure that there is a system for keeping information up to date.
- Ensure that all relevant agencies are aware of procedures for signposting carers to support and services.
- Develop methods for checking that information is being received by the right people and is understandable.
- Develop a carers' information network.
- Work with local carers' organisations to keep contact details for carers (with their consent) so that information, newsletters, etc. can be posted to them. Make a note in the cared-for person's record whenever a carer's assessment is refused, giving the reason, so that there is evidence that one has been offered and an indication of why it has not been accepted.
- Carers who refuse assessment may still want to have an emergency plan in place.

- Ensure that an offer of assessment is made on a regular basis (e.g. at the cared-for person's annual review or following a change of circumstances).

Research and policy

There are lots of ways in which information can be provided so that it is more likely to reach people who may not otherwise know about their rights as carers. Through the multi-agency strategy, statutory and local voluntary agencies should work together to develop an information strategy. Heron (11) details the necessary components of an information strategy and advocates the following stages:

- deciding what information is needed when, and who is responsible for it
- designing and planning the information
- distributing the information
- monitoring the uptake and effectiveness
- keeping it up to date.

In addition to being distributed through specialist services, information should be made available via any number of local resources (e.g. supermarkets and shopping centres, libraries, GP surgeries, leisure centres, schools, community centres, places of worship, clinics and hospitals) and in different formats (e.g. recorded voice, easy read, different languages). Local and national media (e.g. radio, internet, press) should be used to publicise carers' rights.

In recent years, a lot of effort has been put into developing information for carers. However, a strategic approach is necessary to ensure that it is received by the right people at the right time. (11) A recent study by the Audit Commission (12) found that, while a great deal of information is available for carers, it needs to be provided in a more systematic way. For instance, people who have just become carers need information on where to get help for themselves and for the person they are caring for. (11)

In addition, many carers of people with learning disabilities have not been assessed because the cared-for person is already receiving services. As a result, the trigger for a carer's assessment – a community care assessment – is absent. (13) This emphasises the importance of well-coordinated, up-to-date information for all those in contact with carers so that carers can become aware of their right to request an assessment.

Previous practice guidance sets out responsibilities for local authorities in relation to the provision of information for social care.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- Local partnerships in Surrey have set up a website to provide information for both carers and professionals. (12) It hosts Care Radio, an internet radio station for carers, and is also linked to the national website run by Carers UK.
- Many local authorities have set up one-stop shops that are able to offer information on a range of services and benefits. Staff who have first contact with customers are able to ask them if they have caring responsibilities. However, one-stop shops may work less well in rural areas.
- All referrals in Devon, including all first-contact details, will soon be taken through Care Direct. When appropriate, callers will be asked if they have a carer or if they have caring responsibilities.
- In Sunderland, a multi-agency approach to planning events for Carers' Week and Carers' Rights Day has ensured good local publicity.

Identifying hidden carers

Key research and policy findings

- People who carry out caring responsibilities do not always recognise themselves as 'carers'(11) .
- Health professionals are in a key position to identify hidden carers.
- Health professionals do not routinely refer carers to social services(12).
- Participation strategies that rely on consultation with those who already receive services are likely to further marginalise hidden carers(5).
- Black and minority ethnic communities would welcome the involvement of their community representatives in providing them with information about available services(14).

Practice points

- Ensure that any information strategy includes additional key partners (e.g. local pharmacies, welfare benefits staff).
- Develop a local profile of carers based on available information (such as the Census) and use this information to identify target groups. Where possible, include details of diversity (e.g. ethnicity, age, sexuality).
- Ensure that information is produced in a variety of formats and is targeted to minority communities in the locality.

- Ensure that GP surgeries in your area have strategies for identifying hidden carers and, with their consent, referring them on to local support services.
- Promote joint working with other local services (e.g. through the secondment of carers' support workers to GP surgeries).
- Make links with schools and local youth services to raise awareness about young carers.
- Target the carers of people with mental health problems through the local psychiatric service.
- Target carers through voluntary organisations (e.g. Mencap, Mind, Scope, MS Society, Alzheimer's Society).
- Ensure that all adult assessments clarify whether the person being assessed has a parenting role(7)(8).
- Use a variety of resources to raise awareness – e.g. radio, internet, local meetings, outreach work, posters and leaflets.
- Involve the local press in promoting awareness about carers' issues.

Research and policy

Carers may not see themselves as being in need of services. Many may feel that they are simply carrying out ordinary responsibilities as part of a family, this is the case particularly with black and minority ethnic carers(14). Many carers of people with learning disabilities have continued their caring role well into their child's adulthood and may not see themselves as carers but simply as parents. Carers of people with stigmatised conditions (e.g. mental health problems, drug and alcohol problems) may be reluctant to make their needs known. It is important that local authorities are prepared to support vulnerable people should the informal care arrangements break down, thus finding hidden carers is an essential part of providing proper emergency cover.

It is not, therefore, sufficient to rely on carers to identify themselves(15). The use of the word 'carer' in itself may be problematic for people unfamiliar with the term(6)(11). A number of writers have suggested that leaflets should ask: 'Do you look after someone?' rather than 'Are you a carer?'

Some carers may view the assessment process as a way of checking up on their ability to care, (6) and this may discourage them from approaching social services. Carers may be more comfortable approaching voluntary sector providers for help because this avoids the stigma associated with accessing statutory services. Word of mouth is very powerful(6), and once carers have positive experiences and outcomes, they may encourage others to seek help. Black and minority ethnic groups are less likely than others to be aware of the systems within public services(14), and carers in these groups may have less awareness of their rights.

Many carers are likely to have first contact with the health service. (16) GPs and pharmacies are in a key position to make contact with hidden carers. This highlights the importance for local authorities of working in partnership with health services when identifying hidden carers. The new General Medical Services contract for GPs encourages identification of carers and their referral to social services(17).

The Audit Commission report (12) found that, while carers found GPs helpful, the latter were not generally referring carers to social services. The Princess Royal Trust for Carers has published a good practice guide (18) that outlines methods for involving local health professionals in the identification of hidden carers. *Caring about carers: a national strategy for carers*) offers a checklist (16) for GPs and primary care teams.

Previous practice guidance (2) offers a sample referral form that can be used to identify hidden carers within a locally agreed protocol. The agreement of such a protocol should increase awareness of referral procedures and the development of a shared understanding between related authorities. It may prove particularly useful where the cared-for person refuses contact with social care professionals. The protocol would allow others - for example, GPs or voluntary sector workers – to verify the eligibility of the carer.

A study in 1997 (5) emphasised the importance of concentrating on centres that ordinary people use in targeting hard-to-reach groups, as this will help to identify those who do not see themselves as carers. Minority community leaders were approached to arrange meetings in appropriate community centres. Culturally appropriate food was offered and a range of translation facilities were made available. It should be noted that community leaders may not be able to represent the views of all the people in their community, but they may be helpful in assisting initial contact with carers in more inaccessible groups.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- Provider agencies that have contracts with the London Borough of Tower Hamlets pass on monitoring and statistical information about carers on a monthly basis. With the carers' consent, the local authority is informed of their caring role. Tower Hamlets have also developed a discount card scheme to encourage carers to make themselves known to social services: 'The scheme offers a package of discounts (negotiated at no financial cost to the council) on a range of local goods and services, including discounts on chemists' goods, ironing, cleaning, reflexology, other alternative therapies, cinema and other leisure facilities and restaurants. Upon registration the carer is also encouraged to have a carer assessment. The authority then has a record of the number of carers who accepted or declined a carer assessment'(12).
- Carers' emergency schemes can be useful in encouraging carers to engage with services, especially where no other services are received. In 1997, West Sussex was successful in identifying large numbers of hidden carers through

its Adult Carers Mobile Information Service(19). The project was originally funded by the Lottery, and due to its continued success and expansion – today it covers the whole county – it is now funded by West Sussex County Council through the Carers' Grant. The project consists of a mini-bus and staff who offer a mobile information service for carers. The service is a first point of contact and carers are referred on, with their consent, to a network of carers' support organisations in the area coordinated by the West Sussex Carers Network. The service aims to vary the times and places it visits to increase the numbers of people it reaches out to. Some staff work both on the bus and within the carers' support network, providing a link between the information service and the members of the West Sussex Carers Network.

- Camden Social Services has commissioned two voluntary sector organisations – the Princess Royal Trust Camden Carers Centre and African and Caribbean Elders – to provide a carers' support service within the Royal Free and University College London (UCL) hospitals. The service is specifically aimed at those carers requiring support with the hospital discharge process. The workers receive referrals in a number of ways – for example, from social workers and consultants, via multidisciplinary meetings and by visiting wards both during the day and in the evening to talk to visitors. The workers are hospital-based and support the carer during the patient's hospital stay right through to discharge, and in the initial stages following discharge. The carer may then be referred for more long-term support from the local carers' centre or other carers' organisations. The aims of the support service are to:
 - raise awareness of carers' issues among all health professionals in the hospital
 - identify carers and support them with the discharge process
 - encourage take up of carers' assessments
 - signpost carers to appropriate support services within the statutory and voluntary sectors
 - provide an advocacy role if required
 - ensure that discharge planning meets the needs of both patient and carer
 - prevent re-admittance
 - help sustain the carers' ability to care.
- In Norfolk, Crossroads runs a 24-hour helpline for carers. In partnership with other Crossroads schemes across the county, it gives carers access to short breaks at short notice and supports a range of information provision and outreach to hidden carers. In 2004/05, the development of the helpline included negotiating a research and policy project for the Norfolk Drug and Alcohol team

to identify the support needs of carers – including young carers – of drug and alcohol abusers.

- During Carers Week (13–19 June 2005), Sunderland Carers Centre prepared four quick questions to ask callers who telephoned the Council's People First Contact Centre. Out of 431 people who agreed to answer the questions, 41 new or 'hidden' carers were discovered who weren't aware of what support was available.
- Wigan Metropolitan Borough Council set up a GP registration scheme for carers with the aim of identifying hidden carers, the scheme was based on 'Primary Carers – identifying and providing support to carers in primary care' Princess Royal Trust for Carers, 2003.

The scheme has led to the registration of over 1,000 carers. Every carer registered gets a questionnaire and as a result is sent a tailored information pack depending on the needs identified. Information from the questionnaires has led to the provision of carer training, an increase in take-up in services funded by the carers grant and increased carer participation.

- Hertfordshire County Council has produced a DVD called *Getting in touch* to help minority ethnic carers. There are versions in English, Gujarati and Punjabi. Online clips are available at www.hertsdirect.org/carers
http://multimedia.hertsdirect.org/site/player/pl_compact.php?a=4549&t=0&m=wm&l=en_GB
- In St Helens the council has organised a series of community events to promote wellbeing and benefit take-up. Many people attended and were able to access information and advice on a number of things such as falls prevention, healthy eating, support for carers and benefits advice.

The revenues and benefits team were able to demonstrate that people who could not receive Carer's Allowance because of other income from work or pension could, because of their underlying entitlement to the benefit, claim a carer's premium on council tax and housing benefit and a number of other means-tested benefits.

Young carers

Key research and policy findings

- Young carers are largely hidden and it is therefore very difficult to give accurate figures about their numbers. In the 2001 Census 175,000 children and young people in the UK were identified as carers. **(20)**
- Young carers are being increasingly recognised in government policy.
- The Home Office report *Hidden harm* **(21)** estimates that, in the UK, there are

between 250,000 and 350,000 children of problem drug users. These children are not necessarily carers, but many may be taking on responsibilities that are disproportionate to their age.

- Being a young carer can have detrimental effects on young people, including problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems a secret, problems with transition to adulthood, lack of recognition and feeling they are not being listened to. (22,23)
- 27 per cent of carers of secondary school age experience some problems at school. (24)

Practice points

- Recognise that, although young people should not have caring responsibilities that are inappropriate to their age, some do and will still need support.
- Ensure that the multi-agency strategy addresses the needs of young carers and, where possible, is linked to the Children and Young People's Plan for your area.
- Have in place a protocol, shared between adults and children's services, for identifying and assessing young carers.
- Consider whether the young carer is a 'child in need' under the Children Act 1989.
- Ensure that all staff are aware of procedures for reporting child protection concerns.
- Adopt a whole-family perspective, working jointly with statutory services for children and adults, voluntary services, education and (for children of 13 years and older) Connexions.
- Ensure that all assessments of adults include a check to find out if there are children in the family who either take on, or are at risk of taking on, a caring role.
- In line with fair access to care services (FACS) guidance, ensure that adult services support disabled people in their parenting role.
- Ensure that the authority has a senior lead on young carers to resolve promptly disputes between adults' and children's services.
- Offer welfare rights assessments to 16- and 17-year-old carers.
- Through the information strategy, ensure that young carers and practitioners have information on sources of support. Some information about support is available on the Young Carers Initiative website.

Research and policy

There is widespread agreement that children should not be undertaking regular and substantial caring responsibilities or inappropriate personal care tasks. Local authorities have a responsibility to ensure that the person needing care has appropriate services and this should include help with parenting tasks. (7) There is evidence, however, of large numbers of young carers. In the 2001 Census, 175,000 children and young people in the UK were identified as carers. (20) The average age of young carers supported by projects in the UK is just 12 years. (23,24)

Young carers are:

children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks. (23)

Problems arise when the level of responsibility taken on by the young person is inappropriate to their age and maturity. Practitioners should be aware that young carers, having taken on roles beyond their years, can present as more mature than they really are. The impact of caring on the young person is an important consideration and could be influenced by a number of factors, such as family circumstances, the age of the young carer, the amount and type of care given and, crucially, whether the cared-for person has adequate statutory or other sources of support. Becker and Dearden (24) offer an analysis of the number of hours spent caring by children of different ages. Findings indicate that 84 per cent of young carers provide 1 to 19 hours of care per week, 9 per cent provide 20 to 49 hours and 7 per cent provide more than 50 hours.

Caring about carers: A national strategy for carers (16) recognises that, while support must be offered to the cared-for person, young people may continue to play a caring role that can have a detrimental effect on them. Even when the care provided is adequate, children may be affected in other ways - for example, by feeling guilty about leaving their parent alone or worrying about their parent's welfare or financial concerns. The national carers' strategy identifies what young carers need:

- recognition of their role
- information about the support available to them
- support with caring tasks
- emotional support - especially someone whom they can talk to about their feelings. (16)

The framework for the assessment of children in need and their families (25) advocates a holistic family approach to assessment, facilitated by joint working. This framework should be used if it appears that a child is 'in need' under the Children Act 1989. The government's commitment to supporting young carers is evidenced in the Carers' Grant guidance, where it states its objective is to 'support children and young people who are carers in having a break from caring; or fund voluntary organisations to provide breaks directly on the basis of their own assessments'. (26)

Thirty-five per cent of young carers are 16-17 years old **(24)**. This group has needs that differ from those of younger carers, particularly in light of the 2004 Act's requirement to consider training, employment and leisure needs during assessment. There is evidence that young carers are more likely to experience problems with transition into adulthood:

The main factors that influence young people's caring experiences and transitions to adulthood are [thus]: service receipt, family income, the nature of parental illness or disability and family structure. **(23)**

The policy guidance **(3)** refers to circumstances where it may be appropriate for carers aged 16 or 17 to take on aspects of the caring role - for example, when a parent is terminally ill. Such young carers should be properly supported to ensure that caring is a positive experience for them. Practitioners will need to make carefully considered judgements about the caring tasks to be carried out by young people, but they should not include inappropriate personal care. The aim should be to empower parents and minimise the caring role of the young person in a way that is appropriate to their age. The role of young carers should be acknowledged but not encouraged, and the views of young people should be taken into account.

Identification of young carers can be problematic. Many children live with family members with stigmatised conditions such as mental illness or drug and alcohol problems. In many cases, families fear what professional intervention may lead to if they are identified. **(23,27)** Some families may also have concerns about the stigmatisation of being assessed under children's legislation. **(27)** If a young carer requests an assessment under the 1995 Act **(1)**, the local authority must carry out one. As a matter of good practice, however, and in line with Children Act 1989 guidance, the *Framework for the assessment of children in need and their families* **(25)** - see particularly paragraphs 3.61-3.63 - should be used as it provides for a more holistic assessment under the Children Act 1989. The policy guidance **(3)** states that 'the new obligation to consider a young carer's wish to work or undertake education, training or leisure would still apply,' regardless of the legislation under which they were assessed.

Adult services, in addition to supporting disabled parents, have a key role in identifying young carers, as they will often be the first point of contact. At the point of assessing the cared-for person, adult services must ask whether the person they are assessing has children **(8)** and, if they do, what impact they feel their disability has on them. **(27)** Some children live with disabled siblings or grandparents and take on some caring responsibilities to support their parents who are the main carers. In the absence of their own parents, other children may live with grandparents who have care needs.

Many young carers have problems at school, including poor educational performance and difficulty fitting in with their peers. **(23)** Such problems may be a consequence of poor attendance at school and the pressure and stress caused by caring responsibilities. Although there has been a gradual decrease in absence from school among young carers since 1995, between 13 per cent of those of primary school age and 27 per cent of those of secondary school age are still experiencing some problems at school. **(24)** In addition, when families include someone with a disability the family

income is likely to be lower than average, this may affect the young person's opportunities for further education.

These issues highlight the importance of partnership working between adult and children's services, voluntary sector, young carers services and education professionals. It is important that practitioners adopt a whole-family approach to the assessment of young carers, and joint working is vital for this to happen. Locally agreed protocols should support joint working and avoid disputes regarding assessment and/or financial responsibility. Although not a requirement, the appointment of a senior lead on young carers - with the authority to make decisions on any disputes - would facilitate seamless service provision.

The majority of support for identified young carers is funded through the local authority and provided by the voluntary sector. **(23)** Available support includes:

- breaks and activities
- evening clubs
- access to information and advice
- prevention work with families
- mentoring.

The voluntary sector is a valued source of support to many young carers and their families but it should not be relied on as a substitute for adequate support for the cared-for person. No care package should depend on the inappropriate caring role of a child. The information strategy should ensure that practitioners in both adults' and children's services are aware of resources for young carers. It is also important to acknowledge that young carers may not want to be labelled or directed only to specialist young carers' services such as the ones mentioned above. Mainstream resources should be used where appropriate to provide support for young carers.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- North Yorkshire County Council has developed an **assessment form** with young carers that is user friendly and may be used to assist in the assessment process.
- Young carers in Kent have developed their own **website** which offers information to other young carers. They have also produced a DVD to raise awareness in schools about the issues facing them.
- The Princess Royal Trust for Carers has produced a document to assist with the implementation of the five Every Child Matters outcomes. The paper is broken down into the key judgements most relevant to young carers taken from *Inspection of children's services: key judgements and illustrative evidence*¹.

- The Princess Royal Trust for Carers offers an exemplar protocol for local authority joint assessment and support for young carers and their families:
 - Further information for young carers, their families and professionals is available from:
 - the Children's Society's Young Carers Initiative
 - the Princess Royal Trust for Carers' YCnet
 - the Disabled Parents Network
 - the Surrey County Council guide (see Training packs) on young carers for Connexions staff
 - the Common Assessment Framework (CAF), a national, standardised approach to assessing children and young people.

Section 2: Assessment of carers

The government is well aware that the social care system would collapse were it not for the work done by carers, who make a vital contribution to society by enabling the people they care for to remain in the community. Both the Green Paper *Independence, well-being and choice* (28) and the subsequent White Paper, *Our health, our care, our say* (REF) emphasise the need to ensure that carers are integral to the new vision for social care.

It is vital, therefore, that carers are properly supported and enabled to sustain their caring role. For it to be useful, the carer's assessment must be focused on the desired outcomes stated by the carer him/herself. The policy guidance (3) requires consideration of the carer's willingness and ability to care - of the carer's 'attitude and mental capabilities and not just their physical ability'. For example, some people may be reluctant to take on the responsibility yet feel:

'a moral obligation to do so; others may feel defeated, trapped or depressed. The assessment of the person's willingness and ability to care must also now take into consideration, for example whether the carer works or wishes to work, or undertake education, training or any leisure activity.' (3) (point 43)

Under the 2004 Act, consideration of a carer's needs in these areas - education, training, employment and leisure - is now a requirement. In addition to ensuring that they have full access to mainstream resources, assessors must be aware of the resources that are available - locally and nationally - to support carers in pursuing these activities. 'Signposting' to appropriate resources and sources of help can only be successful if up-to-date information is available for both assessors and carers.

Carer participation - not only in assessment but also in the planning and design of services - is key to providing the type of support that carers want and need. Where there are gaps in services, developing local resources through carer participation should be a priority.

Outcome focused assessments

Key research and policy findings

- Social care policy is increasingly focusing on outcomes for those in receipt of services rather than on inputs and processes.
- Progress towards person-centred, outcomes-focused policy and practice is patchy.
- Being acknowledged and listened to is very important to carers and can be an outcome in itself.
- Progress on carrying out carer assessments is slow, and few separate carer assessments are carried out(12,29).

- Development work is needed to embed the outcomes focus into practice.

Practice points

Assessment

- Provide staff training on outcomes-focused work, with the inclusion of carers as trainers.
- Give carers information about the assessment process, ensuring that they are aware when an assessment is taking place.
- Give carers a list of things to think about (i.e. a self-assessment component) before a face-to-face meeting.
- Use a partnership approach to carers' assessment, allowing carers to identify their own desired outcomes.
- Use open questions and avoid a tick box approach.
- Ensure that carers are made aware of any possible charges before services are arranged.
- Ensure that carers have an opportunity to give feedback on the assessment process.
- Encourage flexibility and innovation in identifying services to meet carers' needs.
- Use an appropriate, outcomes-focused assessment tool.
- Ensure that carers are offered time to talk away from the cared-for person.
- If necessary, arrange for the carer and the person they care for to be assessed by different people.
- Ensure that the carers of those who refuse services are still offered assessment.

A practitioners guide to carers' assessments (8) emphasises that:

- The most important element of the content of the carer's assessment will be the focus on what the carer wants to happen (the outcome).
- The guide outlines the necessary elements of the assessment (pp16-22), including the need to consider the carer's education, training, employment and leisure needs.

Review

- Ensure that there is a review process for carers' assessments.

- Agree a date for the review at the time of assessment. Practitioners' guidance (8) suggests that a review should take place three months after a new care package is initiated and every 6-12 months thereafter.
- Identify triggers for calling an unscheduled review.
- Don't make any changes to services without first carrying out a review.

Research and policy

As part of the government's agenda for modernising health and social care, a raft of legislation and policy initiatives have focused on improving the quality and consistency of social care and promoting independence, control and choice for service users themselves. *Modernising social services* (30) emphasises the need to focus on 'the quality of services experienced by, and the outcomes achieved for, individuals and their carers and families'. Outcomes have been defined as the impacts, effects or end results of services on a person's life (31).

The Department of Health's Green Paper, *Independence, well-being and choice* and subsequent White Paper, *Our health, our care, our say*, are set around seven key outcomes identified by people who use services:

- improved health
- improved quality of life
- making a positive contribution
- exercise of choice and control
- freedom from discrimination or harassment
- economic well-being
- personal dignity.

The Commission for Social Care Inspection (CSCI) has incorporated these into their new assessment framework, *A new outcomes framework for performance assessment of adult social care*.

More specific to carers, Nicholas (31) provides a framework, which is adopted in *A practitioner's guide to carers' assessments* (8), for the evaluation of outcomes for carers. The framework comprises four dimensions:

- quality of life for the person for whom they care
- quality of life for the carer
- managing the caring role
- service process outcomes.

A carer's assessment should be focused on what the carer identifies as the best possible outcome. It must focus on the outcomes the carer would want to see to help them in their caring role and maintain their health and well-being. (8)

For many carers, flexible, client-centred services are essential to the sustainability of the caring role. *Independence, well-being and choice* (28) stresses the need to prevent problems as well as support those with high level needs for care:

In future, greater focus should be placed on preventative services through the wider well-being agenda and through better targeted, early interventions that prevent or defer the need for more costly intensive support. Current eligibility criteria allow for early intervention and support. More use of universal services could help people remain better integrated in their communities, prevent social isolation and maintain independence. This will allow social care to play its specialist and essential role in supporting those with specific needs that cannot be met in this way(28).

The White Paper, *Our health, our care, our say* reinforces this message:

There is also a growing evidence base showing that preventative measures involving a range of local authority services, such as housing, transport, leisure and community safety, in addition to social care, can achieve significant improvements in well-being .

Carers who have time for themselves and flexible services (for example, aromatherapy for relaxation or driving lessons to improve mobility and community access) are more likely to be able to continue as carers. Carers should be offered the same advice and support as care workers in order to protect their own health, for example, with regard to lifting and handling. In the long term, support for carers is likely to save money on costly care packages and residential care.

Previous guidance advocates innovation, stating:

Services for carers are not defined. Any outcome valued by the carer may be a legitimate use of council resources if it genuinely will support the carer in their caring role or help them maintain their own health and well-being(8).

A number of programmes (32,33,34) have supported the development of outcomes-focused practice. These complement the influential work of service-user organisations themselves (35,36) on the processes and outcomes that people want and value.

The work carried out by the Social Policy Research Unit (SPRU) at York University has led to the development of the substantial *Outcomes into practice* resource pack for managers and trainers. (37) Since completion of the SPRU programme, the members of the Outcomes into Practice Network have continued to develop their approaches, providing some examples of current and emerging practice. SPRU was commissioned by SCIE to carry out a knowledge review of the progress on outcomes-focused services for older people (LINK) The review shows

that progress towards person-centred, outcomes-focused policy and practice is patchy and that agencies are at different stages in their implementation. A lot of development work is therefore required to embed this approach into mainstream practice

Research and policy shows that progress on carrying out carers' assessments has been slow (12) and that, where they have been carried out, this is often due to well-informed carers or proactive workers (38) rather than structure in policy and procedure. The Audit Commission (12) found that, where local authorities had returned figures on carers' assessments, they did not correspond with the perceptions of service users or case records.

As the Carers Grant is largely used to provide breaks for carers, some local authorities have tried to find increased assessor resources to facilitate carers' assessments. Without increased resources, it may be difficult for practitioners to meet targets for carrying out assessments. According to the Audit Commission report, (12) social workers with existing heavy caseloads did not see themselves as having time to carry out carers' assessments, and carers were angry about the attitudes of social workers towards them. Some local authorities have delegated their responsibility to carry out carers assessments to local voluntary sector organisations. It is clear, however, that the local authority has a statutory duty to assess and make a decision about service provision: "it is not enough for the local authority to simply check, on a complete or partial basis, the outcomes of another organisation's assessments" (REF combined Policy Guidance for the 2000 and 2004 Acts para 45)

Nicholas (31) states that, to implement outcomes-focused carer assessment, the following are required:

- Culture shift
- Training and support for practitioners
- Additional time to carry out and follow up outcomes-focused carer assessment
- Collaboration with stakeholders
- Opportunities for reflection

Clearly this presents a significant challenge to existing services that are currently working to full capacity. Bearing in mind the consequences of not supporting carers, the measures above should be key priorities for local authorities.

The use of outcomes-focused assessment tools has led to more positive outcomes for both service users and practitioners. Guberman et al (15) carried out an evaluation of the impact of carers' assessment tools in four different countries, which 'aimed at promoting partnership with carers and encouraging greater recognition of the complexities of caregiving and its impact on all aspects of life'.

Models from the UK included the framework for outcomes-focused carer assessment developed by Nicholas(39), which incorporates the tool developed by Nolan et al(40). The latter measures the situation of the carer via three indices for an assessment of the carer's experience of difficulty, satisfaction and managing.

Research confirmed that these tools increased practitioners' insight and understanding of carers' needs and the complexities of the caring relationship, including the positive aspects. For carers, the tools led to the provision of new information and a more person-centred approach. Assessors reported a difference in the power balance. Carers were viewed as partners rather than resources, and professionals took the role of facilitators, while the expertise of carers was recognised(31).

Flexibility and innovation in service provision is necessary for an outcomes-focused approach. Practitioners using the assessment tool noted that asking carers how they would like to make use of breaks led to an increase in new or rekindled interests. The Carers Grant guidance encourages flexibility in suggesting that money could be spent on 'driving lessons, moving and handling classes or a short holiday for the carer' and 'to support carers to move on to new learning and/or work or volunteering opportunities'(26).

Evidence suggests that many carers prefer face-to-face contact to self-assessment, (38) and that being listened to and acknowledged is a valuable aspect of the assessment process and an outcome in itself.

Case study

A disabled woman who cared for her elderly partner wanted to be able to cook him a hot meal in the evenings (lunchtimes were catered for through meals on wheels). This problem was a source of worry for the woman. The assessor simply suggested that the woman buy a microwave and promised to show her how to use it. The woman was willing to buy a microwave herself. The result was that she felt listened to and had got what she needed from the assessment. The desired outcome was achieved with no extra cost to social services.

Informal, face-to-face contact is particularly important to young carers (38) . Preparation forms that help carers plan for their assessment can be useful, but they should not be used to replace the assessment itself. (8) Carers can be empowered to use such forms through advocacy or peer support that is culturally suited to their needs. Face-to-face contact is important to ensure that the carer has appropriate knowledge about the purpose and possible outcomes of assessment. If a carer chooses self-assessment and declines face-to-face contact, the local authority will need to make a judgement, based on the information provided, on whether to provide services.

People who use services and their carers should be offered the opportunity to talk separately. Sometimes there can be tensions between them, and in exceptional circumstances where there are conflicting issues, it may be necessary for the carer's

assessment to be carried out by a separate assessor(41). Carers themselves may have other requirements and should be told that they can have someone else present at the assessment - e.g. a friend, advocate, interpreter, signer(8). Training for assessors should include awareness of issues that may necessitate the allocation of separate assessors.

Where the cared-for person refuses an assessment and/or services, it is important that the carer's needs are assessed. Previous practice guidance addresses this issue (2) (pp 20-21). It may be possible to provide services that support the carer in some way or to work with the cared-for person to help them to accept a degree of service. For example, someone who refuses to accept care from another person may accept a sitting service that allows their carer some time for a break. A carer is still entitled to an assessment even where the person they care for is not eligible for or receiving services. The details of this are explained in Carer's and their Rights.

Where a cared for person receives services that are funded by health through Continuing Care local authorities should still offer a carer's assessment. The legal framework for this is explained in detail in Carers and their Rights.

If a carer refuses assessment, their views should still formulate part of the assessment process for the cared-for person:

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(42).

Transition to adulthood for disabled young people can be a difficult time and is likely to bring about concerns for parent carers. Additional support may be needed at this time (42).

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- A study into supporting carers in employment (29) identified an initiative in which, following assessment, carers are allocated help for a specified number of hours to give them a break from caring. Carers can take these hours on a regular basis or save them for when they are needed. Carers working irregular hours found the scheme particularly helpful.
- A family resource team in West Berkshire Council has been running a pilot of outcome-based working since July 2003. At the beginning, practitioners were required to negotiate outcomes, recording with the person the desired start and end points for each outcome. With the help of a simple tool, the progress towards achieving these outcomes was noted on a scale from 1 to 10. The experiences of those involved in the pilot study have been overwhelmingly positive.

Evaluation found:

- greater clarity at the outset, resulting in a clear set of goals, making it easier to formulate action plans and agree time scales
- active engagement of service users in identifying areas of difficulty and in 'signing up' to try to resolve these
- a breakdown of the power differential, and improved relationships between families and professionals.

In addition, the following were discovered:

- The scaling aspect to the tool was helpful in reflecting on progress made
 - There was potential to provide information about what works for future projects.
 - An outcome-based approach takes time to develop.
 - The identification of goals that are realistic and meaningful to the family is key to the outcomes-focused model.
- In Hertfordshire, one of the ways that the focus on outcomes has been developed is through using the power of the 2000 Act to facilitate flexible use of the Carers Grant. The following are examples of what the grant has been used to pay for:
 - a computer for a carer who could not access computer services from the local library because he felt unable to leave the person he cared for alone
 - repairs/insurance costs for a car, where transport was crucial to the caring role
 - an entry phone with audio/video, where the carer lived in a two-storey house and had mobility problems
 - a £500 contribution to a flight for a grandmother to come from another country and care for a woman with multiple sclerosis. Rural homecare could not deliver cost-effectively, and residential respite would have had a negative impact on the family. The outcome was that 10 weeks of family-friendly care was provided at a cost to the council of £500.
 - In Birmingham, Crossroads manages a moving and handling project. When equipment is delivered to a home, a referral is automatically sent to Crossroads, which sends someone to train the carer in how to use it properly. The project is funded through the Carers Grant.

- In Kirklees carers have been trained to co-facilitate carers' assessment training for assessors and to raise awareness about assessment amongst carers. The carers have formed a 'bank' and can be called upon to attend training and awareness events. Participants are paid for their work and offered support where appropriate. Carers are also involved in development work around assessment and training.
- Torbay Care Trust runs an emotional support scheme for carers. The scheme supports eligible carers who feel they are not coping well and would benefit from talking confidentially to a qualified counsellor, about emotional concerns affecting their caring role. Carers can be referred by care managers. Eligible carers can have up to 10 sessions, free of charge, with a participating, privately practising counsellor and they 'pay' with a voucher each time they go. Ongoing evaluation shows the scheme is beneficial.

One carer stressed the importance of having a scheme like this, particularly as often carers cannot afford counselling. She said of her experience:

"I found the scheme very beneficial. Having moved into the area to care for a family member, I felt isolated and alone. Although it was sometimes difficult bringing up issues in my life, which were not always connected with my caring role, it definitely helped me move on and build my life down here. I feel a different person, much more positive and in control. I hope the scheme continues and that many other carers get as much out of it as I did."

- In Peterborough, moving and handling training is provided to carers on an individual basis in their own home. Trainers have access to small aids provision and may make referrals to occupational therapy.
- In partnership with Carers UK the four Beacon councils for supporting carers (Hertfordshire, Rochdale, Sefton and Sunderland) have produced
- a DVD and training pack for front-line staff to support them in carrying out effective carers' assessments. Trainers, managers and front-line staff had all identified a need for a video-based tool to support training. While the best option is always to involve carers as trainers, the reality is that this may not always be possible, and this DVD ensures the carers' voice is powerfully heard.
- a questionnaire for carer feedback to support outcomes focused assessment. This tool is designed to make it easier for any authority that does not already have a routine process for getting carer feedback. The aim is that a questionnaire like this may one day form the basis of a national measure of how local authorities are delivering actual outcomes, rather than simply measuring processes. Some authorities are already beginning to use this questionnaire.

<http://beacons.idea.gov.uk/idk/core/page.do?pagelId=6283626>

- a balanced scorecard. This tool is designed to assist authorities in identifying how their carers' strategies are delivering on the seven strategic outcomes of the White Paper. It will also give a structure for discussions with business relationship managers on these issues. The tool is available at <http://www.beacons.idea.gov.uk/idk/core/page.do?pagelId=6283626>

Promoting access to education, training, employment and leisure

Key research and policy findings

- The benefits of employment to carers are well documented and include better income, pension rights, career prospects and social networks.
- Evidence shows that carers generally have poor knowledge about pensions and that they tend to prioritise based on current financial pressures (ref Arksey et al 2005)
- Employment, education and training can be beneficial to carers' emotional and physical well-being, boosting self-esteem and reducing the risk of social exclusion.
- Good-quality, flexible support is needed for carers to be free to fulfil their employment, training, education and leisure needs.
- Awareness-raising is needed to ensure that carers' needs are supported in the wider society.
- Support to remain in employment is identified as a key outcome by many carers(29).
- Carers need support to prepare adequately for employment especially where confidence may be lost due to the length of the caring role.
- Opportunities to engage in leisure activities can be significantly reduced by the caring role (ref: Stevens et al)
- Engagement in leisure activities promotes physical and psychological well-being (ref: Stevens et al, 2004. need to enter)
- For parent carers work is important in 'maintaining a personal equilibrium and in participating in normal life' (ref Steill et al 2006)
- Parent carers may need additional and focused support particularly at the time of transition to adult services (ref as above)
- The Childcare Act 2006 requires local authorities to assess the local childcare market and to secure sufficient childcare for working parents. Childcare will only be deemed sufficient if meets the needs of the community in general and in particular those families on lower incomes and those with disabled children.(source surestart http://www.surestart.gov.uk/_doc/P0002262.doc)

Practice points

- Ensure that practitioners and carers have access to up-to-date information on local resources for supporting carers in education, training, employment and leisure.
- Ensure that carers are offered appropriate support for the cared-for person so that they can have the peace of mind to pursue their own interests. This should include support services outside normal day centre hours and support after school and during school holidays for disabled children.
- Ensure carers are supported to plan for emergencies.
 - Assess whether carers need funding for fees and transport when accessing education and training.
 - Offer assessments at flexible times to accommodate those in employment.
 - Offer welfare-rights assessments to carers wishing to take up employment, education or training opportunities.

Research and policy

Research shows that carers are more likely to lack confidence and self-esteem (43). This, in addition to their availability, is likely to disadvantage them in taking up education, employment or leisure activities.

Many carers have been out of the workplace for some time and may need to build skills and confidence before considering work. It is important that people are supported to prepare themselves for a return to the workplace(44), and this should include people whose caring responsibilities have come to an end. Preparation through training and work placements can avert problems in paid employment(43). Learning for living (see below) is a City and Guilds course specifically designed for this purpose.

Learning for living is an online learning resource that can lead to a qualification accredited by the Qualifications and Curriculum Authority. The Level 2 Certificate in Personal Development & Learning for Unpaid Carers is designed to identify and build on the knowledge, understanding and skills of people who are unpaid carers, either currently or in the recent past.

The award provides carers with an opportunity for self-development and confidence building, to prepare for other roles and choices and to transfer the skills acquired from the caring role.

Delivery is via approved City & Guilds centres (either distance learning or at a centre), and is potentially fundable by the Learning and Skills Council in England and by Education and Learning Wales.

Education can be for pleasure, to support carers in their caring role (e.g. learning stress management or correct lifting and handling) or as part of a plan to return to employment. It may or may not lead to the gaining of qualifications. Carers may also see time for study as a break from their caring responsibilities.

Flexible support services enable carers to remain in work (16,45) and facilitate their access to education(44). Services may include voucher schemes for short-term breaks, which offer increased flexibility, or the use of direct payments. Distance learning may be more appropriate to the needs of some carers. Many carers are on low incomes and may need support with costs for transport or college fees(44). Action for Carers in Employment have successfully campaigned for a reduction in education fees for carers and for courses targeted at them(44).

Carers, just like other people, may work shifts and weekends and may need support outside normal working hours(29). Certainly such support must be available to meet leisure needs. If carers are to achieve their desired outcomes with regard to employment, education, training and leisure activities, new and flexible outcomes-focused services will need to be developed in line with local need. In a survey for the Department of Work and Pensions Arksey (ref 2005) found that some services in particular would support carers to combine work and care. These include: longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic chores.

Carers' participation in the planning and provision of local learning resources is essential to ensure that it fits with desired outcomes(44). Courses may need to be targeted at certain local groups and offered at times when carers are more likely to be able to participate. The involvement of carers will play a vital part in the development of flexible services, which, in turn, will enable carers to participate more fully in society.

Many carers say that they are restricted in what they do because of concern that something unforeseen might happen(46). For example, if a carer has transport problems or is taken ill, who will support the person they care for? There is evidence that such uncertainties influence the decision making of carers with regard to work and retirement (ref Arksey et al 2005). Carers emergency schemes are important to give carers peace of mind to pursue their desired daily activities. Previous guidance (8) has highlighted the need for contingency planning and in the White Paper *Our health, our care, our say* the government gives a commitment to ensure that short-term, home-based support is made available to carers in crisis or emergency situations.

Case study

A carer raised concerns about the stress caused by her uncertainty of what would happen in an emergency. She was unsure who to contact to provide care for her son who is profoundly autistic and has pica syndrome.

The carer had recently been in an emergency situation: her partner had had a heart attack while her son was at home with her. Although she had managed to cope on this occasion, she felt it would be useful to establish a plan and identify how best to manage such a situation in the future.

A meeting was arranged and an emergency strategy was devised as part of a carer's assessment.

Result: A carer who feels listened to and supported and has peace of mind, at no cost to social services.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- Islington Carers' Forum offers a series of sessions under the title Getting family carers back to work to encourage people to think about the world of work.
- The North West consortium of Crossroads schemes has been working to develop a regional training centre with the support of Skills for Care North West Region. The centre is currently based on a mix of e-learning and face-to-face training. Carer support staff are currently the focus of the training and training for carers is being developed by:
 - making training available for carers to help them in their current role as carers (e.g. moving and handling training, specific condition training, personal development training)
 - planning to train carer volunteers, who will provide training courses to health and social care staff
 - working locally to support carers back into education and work.
- Milton Keynes Crossroads has set up an after-school club in partnership with a local school for children with profound disabilities. This allows parents to extend their day-time activities, including work. European funding via the Action for Carers and Employment initiative is facilitating the expansion of the project to five days a week.
- Isle of Wight Crossroads, with European Union funding via the Action for Carers and Employment initiative, is planning to provide short-notice working-

day cover for carers who would otherwise need a day off work.

- In Bolton, the Learning Ambassador initiative was developed by Carers Support in partnership with Bolton Community College. The scheme offers support to carers through monthly lunch meetings where carers have fun through sharing their skills and experiences and participating in training. The Learning Ambassadors have information stands at community events and run activity-based workshops for carers. Many are members of local committees on other issues.
- The Lions 'message in a bottle' scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location – the fridge. This can give peace of mind to carers, knowing that if they are away from the home in the event of an emergency, the attending services will have all the information they need.

Bottles are free of charge and can be obtained from a number of places including: chemist, doctor's surgery, Age Concern, council offices, housing associations, police stations or through a neighbourhood watch group.

For further information contact Lions International. Telephone: 0845 833 9502. Email: miab@lions.org.uk Website: www.lions.org.uk

- In Sefton a lifelong learning and training officer is funded jointly from the carers grant and training to support carers to access training and education.

Carers are also offered places on all mandatory training provided by the Health and Social Care training unit.

Training includes: understanding Parkinson's disease; manual handling; disability awareness; introductory dementia awareness; alcohol and older people, food hygiene, creative alternatives (therapeutic alternatives to help people with depression) and person-centred planning

Other courses provided through the PCT Expert Patient/Carer Programme include the management of long-term conditions and medication.

The self-management courses have been run in Southport and Formby and South Sefton and are designed to help patients to:

- improve their ability to cope with pain
- manage medication
- reduce levels of depression, fatigue and anxiety
- improve communication with health professionals
- aid independence and mobility
- improve job/voluntary work prospects
- improve and maintain quality of life

The courses consist of six weekly, two and a half hour sessions with support and advice around:

- relaxation techniques
 - diet and nutrition
 - exercise and fitness
 - symptom management techniques
 - communication skills
 - problem solving
 - goal setting
 - action planning
-
- Newcastle carer's centre have a 'pamper room' where carers can receive alternative health therapies such as Indian head massage and reflexology. This free service is much appreciated by carers.

The Carers UK resource pack

Carers UK has produced a resource pack for local authorities and wider use. It contains the following resources:

- an introductory flyer on the Carers (Equal Opportunities) Act 2004, published by Action for Carers and Employment (ACE)/Carers UK, which explains how the resource pack can support its implementation
- *Carers and their rights* by Luke Clements
- Training resources on the *Supporting working carers* CD-ROM:
 - employers' guide
 - carers' guide
 - guide for union representatives
- *Juggling work and care*: a DVD with case studies from employers and carers
- the information booklets *Carers at work* and *Juggling work and care*
- flyers on access to learning from City & Guilds, Open University, National Extension College, Elizabeth Nuffield Foundation (for Philippa Russell's new guide on access to learning for carers)
- Carers UK information and publications list.

The resource pack has been sent out to local authorities, and can be accessed via the ACE website and the Carers UK website.

With the exception of the DVD (which is available on order free of charge), the pack can be downloaded. To support implementation, printed copies will also be distributed through the Carers UK associate membership and ACE networks.

Signposting to other agencies

Key research and policy findings

- Care managers are not always aware of the network of services that can help carers. (2)
- Carers are often unaware of how to access help(17).

Practice points

- Produce an A–Z of carers' services so that assessors have good sources of up-to-date information to enable them to support carers to access opportunities in training, education, leisure and employment.
- Publicise information about services for carers on the local authority website.
- Ensure that assessors are aware of local and national sources of funding for carers' services.
- Ensure that other public bodies are also equipped with signposting information.
- Approach community leaders to facilitate signposting in black and minority ethnic communities.

Research and policy

The practice guidance to the Carers and Disabled Children Act 2000 (2) outlines the necessary steps that local authorities need to take to ensure that carers are well informed about services, resources and other sources of support in their area. In the light of the 2004 Act, information will now need to include services and sources of support that enable carers to access education, training, leisure and employment.

The White Paper *Our health, our care, our say* gives an undertaking to establish: 'A dedicated helpline for carers [that] would offer information in the widest sense – from legal entitlements, to contact numbers for “help” groups and training, to advice on benefits.'

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- Sunderland City Council has an online guide *Opportunities for carers* that gives comprehensive information on local resources for leisure, learning, volunteering and work.
- Hertfordshire County Council has produced fact sheets for social workers that list local and national agencies offering services, information and support to carers.

Useful websites

- **do-it.org.uk** : information about volunteering as a stepping stone to work
- **nextstep** : advice on learning and work
- **Jobcentre Plus** : integrated work and benefit services
- **Action for Carers and Employment (ACE)**: a national pressure group campaigning for better and more flexible services that enable carers to work; led by Carers UK
- **learndirect** : online courses
- **Learning for Living** : City and Guilds courses for carers
- **Learning Skills Council**
- **Contact a Family** : support for parents of disabled children
- **Hertfordshire County Council - Carers** : online information for carers
- **Crossroads Association** : local schemes to support carers in many ways, including the development of training and employment opportunities for carers
- **Princess Royal Trust for Carers** : a network of local centres providing employment support
- Department of Work and Pensions:
 - **benefits and services**
 - **information on the Carer's Allowance** , including an online claim form
 - **worktrain** : information on jobs, careers, learning and training.

Developing local resources

Key research and policy findings

- Support is needed for community groups to develop their skills, knowledge and abilities to enable them to get involved in local service development(47).
- Local and health authorities have limited capacity to respond to emergency situations and arrange short-term support(29).
- Some reasons for carers' inability to take up community care services are: lack of availability, poor quality services, waiting lists, charges and lack of service flexibility(17).

- Many carers have said that they need help with managing direct payments and with their responsibilities as employers(17).

Practice points

- Gather information on the numbers of carers in the locality. Where possible, include information on their employment status, ethnicity, age, sexuality, etc.
- Carry out an audit of local provision.
- Identify gaps in provision, particularly where there is inequality between groups.
- Develop a commissioning strategy with local partners to meet the identified gaps in service.
- Encourage participation from diverse community groups in developing services to meet the specific needs of their communities.
- Ensure - through partnerships and the role of the carers' lead - that mainstream services are accessible to carers.
- Develop, with the voluntary sector, a carers' emergency scheme.
- To inform future development, record circumstances where desired outcomes cannot be met.
- Promote direct payments by providing a support service.

Research and policy

If services are to focus on outcomes, and flexibility is to be made available to carers to sustain their caring role, services need to be developed locally to meet identified needs. This will necessitate not only the identification of local needs and gaps in service, but also the development of community involvement in meeting those needs. Services cannot hope to meet the needs of carers unless all stages of planning and development have active participants with a carer perspective.

Carers exist in all communities, and their needs will be different depending on certain characteristics - for example, cultural diversity, sexuality, age. It is important that they are included in the development of local services to meet their own needs and that they are empowered to become fully participative citizens.

Independence, well-being and choice (28) emphasises the need to use the wider resources of the community when planning care. Early intervention and prevention are also key to the new vision for social care outlined in *Our health, our care, our say..* Participation on a local level, in developing services to target local need, may address many of the issues associated with social exclusion.

The government is clear that the involvement of members of the community with public bodies is vital to the implementation of its policies. Local authorities need to mobilise local communities into active participation. *Firm foundations*(48) a government report on capacity building, sets out a framework for development. The report defines community capacity building as:

activities, resources and support that strengthen the skills, abilities and confidence of people and community groups to take effective action and leading roles in the development of their communities.

Local authorities need to ensure that support is available to local communities to enable individuals and groups to develop the skills and confidence to facilitate active participation(47). Community involvement in decision-making and the setting of local priorities is essential to the implementation of policy at a local level. Communities across the country differ greatly in terms of geography and the diversity of the local population, and such differences are key to the development of appropriate local implementation plans.

Richardson and Sefton (47) offer the basis for a tool for the assessment of capacity-building schemes. They have identified four elements of a successful community group:

- shared vision
- the internal dynamics of the group (including strong leadership, good balance of skills, commitment, enjoying working together and good teamwork)
- relations with the local community
- external support.

They have also ascertained the characteristics of a favourable external environment necessary for the success of community groups:

- financial and other resources - including support with accessing grants
- networking - sharing of skills, contacts and information
- participation in wider activities and projects
- capacity building - i.e. support from external bodies.

Resources need to be evaluated by carers in terms of their outcomes for carers.

Direct payments have, for many disabled people, offered increased independence and choice. If direct payments are to be successful, it is important that people have the support they need to cope with the administrative and human resource management aspects.

Information on direct payments is available from local authorities and from the Department of Health . The main source of direct payments guidance is: '*Community Care, Services for Carers and Children's Services (Direct Payments) Guidance*'.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- Good practice examples of capacity building are to be found in the housing sector where residents/tenants associations have been central to successful regeneration projects. Housing partners in the locality may be able to contribute experience of such projects to the multi-agency strategy.
- Carers emergency schemes (55) - Each carer participating in an emergency scheme will be issued with a card carrying a central office contact number and an identification number. The ID number will relate to records held at the central office, which contain details of the cared-for person, their needs and other appropriate contacts. The office should also have a copy of an emergency plan that has been prepared previously with the carer. Carers UK (46) stresses the importance of a pre-arranged plan and a coordinated 24-hour back-up service. This is far preferable to an emergency card scheme that simply issues carers with a card with contact phone numbers on it. It is also important that people who are offered emergency care are made aware in advance of any likely service charges.

Following on from the commitment in *Our health, our care, our say*, and as part of the new carer's strategy, councils will be expected to develop local schemes to support carers in emergencies.

- The London Borough of Camden has established a project with Camden Crossroads to support Bangladeshi carers. It involves training local Sylheti-speaking residents to be employed as care workers so that Bangladeshi carers are able to take breaks. In this way, it offers a source of employment within the local community as well as providing a service for carers.
- In the Birmingham area, there is a large Somali population. Members of this community, although offered direct payments to purchase care, have had difficulty in accessing culturally appropriate services. Birmingham Crossroads is offering support by training two members of the community to become NVQ assessors, and by employing staff from the community to work at the scheme and become professional carer-support workers. Local leaders believe that the community has the capacity, dedication and enthusiasm to develop its own domiciliary care service. This would be for the community itself initially but would also, in the longer term, have the potential to provide a service for other minority groups in Birmingham. Such a service would be better equipped to make available culturally appropriate services. Crossroads aims to support this venture to ensure that it is able to meet the challenges required by regulation and modernisation. The Crossroads Association has applied for funding to facilitate the employment of a dedicated development worker to work alongside the community, the association and the Birmingham Crossroads scheme.

- In the East Riding of Yorkshire a unit of students on placement was set up to carry out carer assessments. The aims of the project were to encourage work with carers at an early stage whilst addressing capacity issues in care management teams and improving performance indicators. Students were given a two-week induction and the opportunity to observe a carer being assessed. Students were regularly supervised and attended team meetings. They also worked on the duty rota. Monthly meetings were held to review the care plans produced by the students and practice issues were discussed with individual students. The project was evaluated and aims were achieved.

Section 3: Cooperation between authorities

The extent to which carers are disadvantaged can be viewed in terms of the social model of disability, in that it is the barriers in society rather than a person's caring role that restricts them. Inflexible services and lack of awareness, both within and outside social care, can contribute to the social exclusion of carers.

The 2004 Act requires that other public bodies give due consideration to requests from the local authority for assistance in planning services for carers. Cooperation between authorities is essential for the support of carers. It will not only raise awareness among public bodies of their responsibilities towards carers, but it will also encourage society as a whole to support carers rather than leaving it just to social services. There are many things that other authorities can do to support carers, and local authorities - through the multi-agency strategy and the carer's lead - should ensure that awareness is raised.

As large-scale employers, public services are in a position to set an example for good practice in employment. In addition to this, links should be made with local employers to promote a carer-friendly approach to employment.

Provision for carers by other organisations

Key research and policy findings

- Carers' employment needs are rarely considered at a strategic planning level. (29)
- Other public bodies often make the assumption that it is the sole responsibility of social services to meet carers' needs. (29)
- Carers are not covered by the Disability Discrimination Act but, in a landmark case, a carer recently won the right to take her employment case to Europe. The case may have a direct impact on UK discrimination legislation. For more information visit http://www.drc-gb.org/newsroom/news_releases/2007/coleman_case.aspx

Practice points

- Through the multi-agency strategy, involve local partners - health, housing, leisure and education - in strategic planning.
- Ensure that the multi-agency strategy addresses the need for staff training and awareness across all the authorities concerned.
- Ensure that the carers' lead contacts other departments and authorities to find out what they can provide for carers (e.g. 'freedom passes', parking permits for those visiting the cared-for person during the day, carer ID cards for access to discounts, concessionary fees).

- Identify a senior contact point for carers' issues in each public authority.
- Encourage health partners to introduce carer-friendly policies - for example, hospital discharge procedures that take account of carers' employment needs, policies that avoid the cancellation of appointments involving carers, and flexible appointment times.

Research and policy

Employers - as well as partner authorities such as health and housing - often assume that it is social care services' role to support carers. **(29)** However, it is important that carers' needs are recognised and provided for by all sections of society and that social services are not seen as being solely responsible.

The 2004 Act will enable social services departments to be better able to call on other authorities to assist in supporting carers **(3)** (p 13). Key to implementing this are the essential steps of having in place a multi-agency strategy and appointing a carers' lead. The role of the latter is vital to ensure the engagement of other statutory agencies and local resources in supporting carers.

Partnership working can be improved by the secondment of workers between authorities. There is evidence that the placement of a carers' support worker in a GP surgery improves carer access and joint working. **(12,49)** Research into this model has shown that it produces improved awareness of carer issues among surgery staff, quicker interaction and intervention that was thought to have a preventative effect, a more seamless service and carers feeling personally supported by the worker. **(49)**

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- The London Borough of Tower Hamlets has introduced a discount scheme in the locality. The scheme not only helps to identify carers in the area but, by engaging a number of local services, also increases awareness of their presence.
- A health and social care compact has been agreed between the City of Sunderland social services, local health trusts and the voluntary sector.
- Hertfordshire County Council has sent a standard letter to all relevant authorities informing them of their responsibilities under the 2004 Act. A protocol accompanied the letter, and it was suggested that a senior person in each of the organisations signs the protocol agreement.
- In Crawley, carers' support workers attached to the GP service have proved successful in a number of ways, including saving GPs' time**(12)**.

Carer-friendly employment practice

Key research and policy findings

- The UK has over 3 million working carers.

Both carers and employers are likely to benefit from carer-friendly employment policies and significant business benefits can be achieved by using a flexible approach.

- Carers are most likely to be in the age group 45-64 years (**16**) and therefore likely to be among those with the most work experience(**29**).
- Carers may be reluctant to disclose information about their caring role to their employer (ref: caring for sick or disabled children (2006)
- Many carers who are offered the flexibility they need to remain in work respond by making up lost time, working at home and by increased loyalty and commitment (ref as above)
- Almost half of carers are in paid work(**45**).
- Carers are likely to take on work that is below their skill levels and capacity(**29**).
- Flexible working arrangements are essential to ensure that carers can remain in employment(**45,29**).
- Links between employers and statutory services are generally poor(**29**).
- Managers' awareness of family-friendly employment policy within their organisation is generally poor(**50**).
- Family-friendly employment policy is implemented with a degree of reciprocity between managers and carers(**51**).
- The Employee Relations Act 1999 allows employees time off to deal with emergencies (**29**) and 'a reasonable amount of unpaid time off in order to care for dependants'(**45**).
- From April 2007 the Work and Families Act (2006) gave carers the right to request flexible working. Carers UK offer detailed information at <http://www.carersuk.org/Information/Caringandwork/Whatsupportwouldworkforyou>
- Who Cares Wins explores the business benefits of supporting working carers: <http://www.carersuk.org/Policyandpractice/PolicyResources/Research/ResearchWhoCaresWinsfullreport.pdf>

Practice points

- Local strategic partnerships should ensure that links are made with local employers and Jobcentre Plus, with the aim of raising awareness and bringing about attitude change.

- Encourage local partners and employers to use a checklist (Ch 3, point 13) to assess their standards in relation to supporting carers in the workplace.
- Human resources should record and evaluate the ways in which family-friendly policies are interpreted and used in practice.
- Employers that offer flexible working to all employees as a matter of good practice will avoid singling out carers.

Research and policy

Approximately 3 million people in the UK combine caring and work(52). The effects of caring on employment can force carers to work beneath their skill levels, (29) for fewer hours or even stop working altogether.

Extensive research and policy cited by Arksey (45) has shown that employment can enhance the quality of life for carers in a number of ways. Working carers are likely to have better incomes, pension rights, career prospects and social networks. Employment can be beneficial to a carer's emotional and physical well-being and could reduce social exclusion and improve self-esteem.

The benefits for the employer are clear and are outlined in detail in the national carers strategy(16). They include lower staff turnover, flexibility from a more diverse labour pool, improved staff motivation and loyalty and better all-round performance. A study by Yeandle et al (ref who cares wins plus online link) for Carers UK examines the way in which three very different employers have supported carers in the workplace. The study found that the culture of the organisation is key to supporting carers – trust is an important aspect of this. The endorsement of top level management is also necessary in larger organisations. The report emphasises the need to develop a general approach to diversity which includes carers, to provide training and support to managers and to develop internal support networks for carers.

The DVD *Juggling work and care* (53) looks at the 'business case' for employing carers. It explores the way five very different companies support carers and highlights the benefits of this to the employer. Available free from Carers UK , it would be useful for carers' leads when gaining the support of local employers.

Caring will affect almost half of the population by retirement age(54). Therefore, and especially where recruitment is a problem, employers cannot afford to ignore the potential workforce that carers represent.

Organisations will differ in their ability to support carers. Smaller ones, for example, may find flexibility difficult due to the smaller number of other employees to cover. On the other hand, their closeness to their employees may enhance understanding and flexibility(16). There is a need to develop models that will enable smaller-scale employers to support carers(45).

The nature of the work could also have an effect on flexibility. For example, a bank would have less flexibility than a hotel because of rigid opening times. In services with

more rigid needs the staff group are often able to work out solutions themselves that create increased flexibility for all. Work placements for carers can be a useful way of engaging employers and showing them that carers are a valuable resource(43).

Even where carer-friendly employment policies are in place, awareness among employees and managers is low. Carers often rely on the goodwill of managers and on their interpretations of policy to grant leave for caring responsibilities(50,51). Training and support needs to be provided for managers. In addition human resources should record and evaluate the ways in which policies are interpreted and used in practice(50).

Statutory authorities are in a position to set standards for supporting carers in the workplace and should encourage contracted agencies and local partners to develop equally supportive policies.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

- CareWISE is an important strand of Hertfordshire County Council's work/life balance strategy. It aims to provide a range of initiatives to help employees successfully combine their caring responsibilities with work. CareWISE offers all carers working for Hertfordshire County Council the right to request to work flexibly. It also offers paid time off to attend carers' support groups as well as access to an independently facilitated Hertfordshire County Council carers-only group. In addition, carers can take up to five days paid leave to deal with emergencies involving dependants. Further information is available from a Hertfordshire County Council case study and from the Action for Carers and Employment website.

Employers pack

Carers UK website offers information and resources to help promote understanding of the Work and Families Act .

<http://www.carersuk.org/Employersforcarers>

A self-assessment tool for employers is available at.

<http://www.carersuk.org/Employersforcarers/AssessmentToolforbusiness>

Other related downloads are available at:

<http://www.carersuk.org/Employersforcarers/EmployersPack2007/Downloads>

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