

## UNPAID CARERS

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The Equal Opportunities Committee held two roundtable meetings on unpaid carers in 2008. The purpose of the first meeting was to 'gain greater understanding of any areas where unpaid carers feel that they face discrimination'. The second meeting was a chance to follow up some of the issues with service providers and other relevant professionals.

There will be a Committee debate in the Chamber on 25 February 2009 on motion (S3M-3261):

That the Parliament notes evidence gathered by the Equal Opportunities Committee on unpaid carers at its meetings on 25 March and 7 October 2008, which highlighted that there were around 660,000 unpaid carers in Scotland, a figure that represented one in eight of the population; recognises the valuable contribution that unpaid carers make in saving the Scottish economy £7.6 billion a year; further notes that around 40% of unpaid carers surveyed reported that their access to services was poor or that available services did not meet their needs, and calls on the Scottish Government to take into consideration the evidence gathered when developing the forthcoming Scottish Government/COSLA carers strategy.

This paper provides information on unpaid carers in Scotland, including statistics, legislation, policy, and financial support in both Scotland and the UK as a whole. In addition it provides an overview of the issues discussed at the two round table meetings.

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## KEY POINTS

- The Equal Opportunities Committee held two roundtable meetings to discuss unpaid carers on 25 March 2008 and 7 October 2008. The broad aim was to consider the role of unpaid carers in Scotland in terms of access to services, employment and education, and the varied experiences of different groups of carers, such as younger carers and older carers.
- 'Unpaid carer' applies to people who care for an ill, frail or disabled friend, relative or neighbour without receiving paid income. Care can include helping someone bathe or dress, doing housework, or helping people to visit friends and family.
- There are 660,000 unpaid carers in Scotland, 1 in 8 of the Scottish population.
- It is estimated that by 2037 there will be 1 million unpaid carers in Scotland.
- Those providing care over a long period of time are at particular risk of poor health.
- Maintaining paid work is a significant challenge for carers.
- Recent research indicates that more than half of carers in Scotland are currently in debt.
- The contribution of unpaid carers saves the Scottish economy £7.6 billion each year.
- Under the Community Care and Health (Scotland) Act 2002, carers in Scotland have a right to an assessment for services to help them continue caring and balance their caring responsibility.
- Carers in England and Wales have access to Direct Payments to allow them to purchase the services they have been assessed as needing to help them maintain their health and well-being. Carers in Scotland do not share this entitlement.
- The Scottish Government is currently developing a Carers Strategy for Scotland, in partnership with COSLA.
- The Concordat between the Scottish Government and COSLA set out a commitment to 'progress towards delivering 10,000 extra respite weeks per annum at home and in care homes'.
- The Scottish Government published guidance on respite services in November 2008. The main purpose of the guidance is to help local service planners improve short break provision in line with the principles of protecting young carers, enabling self care and working with adult carers as partners in care.
- The Scottish Government funding commitment for unpaid carers for the period 2008-09 to 2010-11 is £9 million, which will be provided to NHS boards to support the implementation of Carer Information Strategies.
- Further funding of £300,000 to fund two festivals for young carers, and £4 million to help deliver 10,000 extra weeks for personalised short breaks for carers a year by 2011, was announced in December 2008.

## INTRODUCTION

The Equal Opportunities Committee held two roundtable meetings to discuss unpaid carers on 25 March 2008 and 7 October 2008. The broad aim was to consider the role of unpaid carers in Scotland in terms of access to services, employment and education, and the varied experiences of different groups of carers, such as younger carers and older carers.

During the discussions there were frequent references to issues which are reserved, such as benefits, but differences in the framework of support for unpaid carers across the UK were also highlighted. In order to provide context to the round table discussions, this paper briefly sets out Scottish Government and UK Government policy and legislative provision regarding unpaid carers, as well as summarising the evidence taken by the Equal Opportunities Committee.

## FACTS ABOUT CARERS

The term 'unpaid carer' applies to people who care for an ill, frail or disabled friend, relative or neighbour without receiving paid income. The type of care provided varies. For example: personal care such as bathing, washing, dressing and toileting; domestic care such as housework, shopping and cooking; and social support, such as trips out to the shops or to visit family and friends.

### *Population of unpaid carers*

- There are 660,000 unpaid carers in Scotland, 1 in 8 of the Scottish population (Carers Scotland 2008<sup>1</sup>)
- Carers are more likely to be women than men. Across the UK, 58% of carers are women (Carers UK 2009)
- Caring varies between ethnic groups. For example, Bangladeshi and Pakistani men and women are three times more likely to provide unpaid care compared with their white British counterparts (Carers UK 2009)
- Young people make up 3% of the total number of unpaid carers across the UK (Carers UK 2009)
- Three in five people across the UK will become unpaid carers at some point in their lives (Carers UK 2009)
- It is estimated that by 2037 there will be 1 million unpaid carers in Scotland (Carers Scotland 2008).

### *Health impact*

- Those providing care over a long period of time are at particular risk of poor health, and both mental and physical health are likely to deteriorate the longer the carer has been caring (Carers UK 2009)
- Unpaid carers providing high levels of care (i.e. more than 50 hours per week) are twice as likely to be 'permanently sick or disabled' as those not caring (Carers UK 2009)
- Unpaid carers not receiving a break are more likely to suffer mental health problems compared to carers who do get a break (Carers UK 2009)

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<sup>1</sup> Carers Scotland in Scottish Parliament Equal Opportunities Committee (2008a).  
*providing research and information services to the Scottish Parliament*

- Many unpaid carers report they are forced to ignore their own health because of a lack of alternative care and the absence of emergency planning measures, for example, if the carer is required to stay in hospital at any time (Carers UK 2009)

### *Financial impact*

Recent research from Carers Scotland (2008a) assessing the impact of the current financial crisis on unpaid carers highlights the following:

- More than half are in debt
- Half of all unpaid carers are cutting back on food just to make ends meet
- Nine in ten (88%) say their financial position is worse than 12 months ago
- Three quarters (79%) are struggling to pay utility bills – up from 32% in 2007
- At the same time the contribution of unpaid carers saves the Scottish economy £7.6 billion each year.

### *Impact on employment*

- Maintaining paid work is a significant challenge for carers, the lack of appropriate support services is the main difficulty as well as the cared-for person not wanting to use care services (Carers Scotland 2008)
- Women are more likely to give up work in order to care for someone (Carers UK)
- Across the UK, 60% of male carers work, 90% of whom work full time (Carers UK)
- 40% of carers across the UK would rather be in paid work but are not able to return to employment because of a lack of reliable and flexible care services and support (Carers Scotland 2008).

## **KEY LEGISLATION FOR CARERS**

### **DUTY TO CARRY OUT CARERS' ASSESSMENTS**

A carer's assessment identifies any help a carer may require in order to continue caring and to balance their caring responsibility with a need to maintain their health, work and family commitments. The assessment is carried out by local authority social work departments.

#### *Scotland*

The **Community Care and Health (Scotland) Act 2002** introduced a range of measures to improve the delivery of care in Scotland. The provisions were underpinned by the principle that carers should be recognised and treated as key partners in providing care. The measures included:

- carers' right to an independent assessment, including for young carers under 16
- a duty on local authorities to inform eligible carers of their right to an assessment
- a duty on local authorities to take account of the care provided by a carer, and the views of the person in need and their carer before deciding what services to provide.

Following a carer's assessment, the local authority shall decide 'whether the needs of the person being assessed call for the provision of any such services' (Section 8).

### *England and Wales*

The **Carers and Disabled Children Act 2000** made four principal changes to the law:

- councils were given powers to support carers by providing services to carers directly
- carers were given the right to an assessment independent of the person they care for
- local authorities were enabled to make direct payments to carers
- councils were given options to support flexibility in provision of short breaks through the short-break voucher scheme.

Under Section 2(1)(c) of this Act, local authorities in England and Wales must consider the carers assessment and 'decide whether or not to provide services to the carer'.

### **DUTY TO CONSIDER A CARER'S WISH TO WORK OR STUDY**

Under the **Carers (Equal Opportunities) Act 2004**, councils in England and Wales must take account of a carer's desire to work or undertake education, training or leisure activities. There is no similar provision in Scotland.

### **RIGHT TO REQUEST FLEXIBLE WORKING**

The **Work and Families Act 2006**, in force since 6 April 2007, extended the right to request flexible working to employees who care for adults (it applies throughout the UK). This built on the introduction (through the **Employment Act 2002**) of the right to request flexible working for parents of children under the age of six (or 18 if the child is disabled). From 6 April 2009 the right to request flexible working is being extended to parents of children aged 16 or under.

## **POLICY ON CARERS**

### **SCOTTISH GOVERNMENT POLICY ON CARERS**

In November 1999 the previous Scottish Executive launched its 'Strategy for Carers in Scotland', which resulted in investment in a range of services to support carers, new carer legislation, and a move to recognise carers as key partners in the provision of care.

Commissioned by the Executive in 2004, the Care 21 Report on the Future of Unpaid Care set an agenda for the next 10 years (2006a). Recommendations were made for the Scottish Executive, the UK Government and other agencies, which included the need for a young carers' strategy; service providers meeting the needs of carers from different cultural backgrounds; and, calls for a UK wide awareness campaign to ensure employers know their responsibilities towards carers and the contribution of unpaid carers.

The Scottish Government is now considering the recommendations from the Care 21 Report together with the commitments of the UK Government's Carers Strategy and is working with COSLA to develop a Carers Strategy for Scotland (Scottish Government 2009a).

### *Young carers*

A young carers policy is also being developed and will form a 'lift out' section within the revised Carers Strategy (Scottish Government 2009b). The Scottish Government and HMIE have also developed a self-evaluation toolkit to help local authorities, agencies, and professionals improve services for young carers and their families (HMIE 2008).

### *Respite services*

In addition to the development of a Carers Strategy for Scotland, the concordat between the Scottish Government and COSLA (2007) set out a number of commitments including 'progress towards delivering 10,000 extra respite weeks per annum at home and in care homes'.

Guidance on respite services was published in November 2008 (Scottish Government). It refers to the concordat commitment, as well as the manifesto commitment that 'by 2011 carers in greatest need will have a guaranteed annual entitlement to breaks from caring'.

The main purpose of the guidance is: "to help local service planners improve short break provision in line with the overall principles of protecting young carers, enabling self care and working with adult carers as partners in care, by:

- improving planning of short break services
- shifting the balance towards preventative support, and
- personalising support to improve outcomes both for carers and those with care needs."

### *NHS Carer Information Strategies*

Under the Community Care and Health (Scotland) Act 2002, health boards are required to develop and implement Carer Information Strategies (Scottish Executive 2006b). These strategies must include measures to improve carer identification and the provision of carer information and support to enable carers to continue in their caring role, whilst protecting their own health. The strategies require Ministerial approval and have been discussed as part of Health Boards Annual Reviews this year (Scottish Government 2009b).

## **UK GOVERNMENT POLICY ON CARERS IN ENGLAND<sup>2</sup>**

The 'New Deal for Carers' (launched in June 2007 by the Department of Health) comprised four key elements:

- reviewing the 1999 national strategy 'Caring for Carers'
- launching an expert carers programme to equip carers with advocacy skills and provide practical training such as first aid, and moving and handling
- launching a helpline for carers – a single telephone number to provide information ranging from national rights and entitlements through to what is available in an individual's local area
- making an additional £25 million available to local authorities in England to enhance provision of short-term, home-based respite care.

As part of the New Deal for Carers, the UK Government published its 'Carers Strategy' in June 2008 (Department of Health). It set an agenda for supporting carers over the next 10 years, addressing health and social care and young carer issues in England, and income and employment matters across the UK. Commitments include:

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<sup>2</sup> Policy is directed at carers in England, except the areas which are reserved, i.e. benefits, which apply throughout the UK.

- providing every carer with the opportunity to access comprehensive information when they need to
- funding for: breaks from caring; young carers; supporting carers to combine employment and caring (see section on funding)
- pilots to look at how the NHS can better support carers in their caring role through developing models of best practice and enabling more joined up provision with local authorities and the voluntary sector.

The identified priorities for 2011 onwards include:

- carers able to access specialist carers' services in every community
- considering extending flexibility in the way personal budgets and direct payments can be used
- reviewing the structure of benefits available to carers in the context of wider benefit reform and fundamentally reviewing the care and support system

## **PAYMENTS TO CARERS**

### **CARER'S ALLOWANCE**

The benefits system<sup>3</sup>, which is reserved, offers a Carer's Allowance which is set at a single rate. There is a statutory requirement to uprate Carer's Allowance each April in line with prices.

In order to qualify for Carer's Allowance, a claimant must be caring for a disabled person 'regularly and substantially'. This is defined in regulations as any week in which the claimant is engaged in caring for 35 hours or more.

The disabled person must also receive either:

- Disability Living Allowance (middle or higher rate component), or
- Attendance Allowance, or
- Constant Attendance Allowance paid with a war or industrial disablement pension.

The current rate (2008-09) for Carer's Allowance is £50.55 per week. A carer is only allowed to receive one award of Carer's Allowance, no matter how many people they are caring for. A person cannot add together the time they spend caring for two or more people. To qualify they have to show that they are caring for one of these people for at least 35 hours a week.

Until 2002, the Carer's Allowance could not be claimed by those over the age of 65, although it remained payable to those who were eligible immediately prior to their 65<sup>th</sup> birthday. The upper age limit for claiming Carer's Allowance was abolished on 28 October 2002.

Claimants will not qualify for benefit if they are working and earning more than £95 per week. Similarly, they will not qualify if they are attending school, college or university for more than 21 hours per week.

As at May 2008, there were 480,730 recipients of Carer's Allowance in the UK, of whom 74% were women (Department for Work and Pensions). In Scotland there were 44,490 recipients of Carer's Allowance, of whom 71% were women. In Wales, there were 31,810 recipients of the

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<sup>3</sup> Information on the benefits system for carers provided by the House of Commons Library.  
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Carer's Allowance, of whom 72% were women. Total UK expenditure for 2008-09 is expected to be around £1.3 billion<sup>4</sup>.

### *Work and Pensions Committee*

The House of Commons Work and Pensions Committee conducted an inquiry in spring 2008 on the effectiveness of the Department for Work and Pensions' existing approach to carers (2008a). The Committee noted the views of many witnesses that the Carer's Allowance is not fit for purpose and many carers were disappointed that the issue was not directly addressed in the Carers Strategy. The Committee received evidence on the desirability of introducing two tiers of support for carers and made this a key recommendation. The two tiers would offer:

- a. income replacement support for carers unable to work, or working only part-time; and
- b. compensation for the additional costs of caring for all carers in intensive caring roles (which would provide some support in maintaining a 'life of their own').

The UK Government responded to the Work and Pensions Committee, stating that it recognised the system of benefits for carers needs an overhaul, but "Rather than consider piecemeal changes to Carer's Allowance, the Government intends to look specifically at the support offered to carers through the benefits system as part of its development of the single benefit". The Committee welcomed this Government commitment to reform benefits for carers, but remained concerned over the absence of an immediate plan and timetable for reform (House of Commons Work and Pensions Committee 2008b).

## **DIRECT PAYMENTS**

Direct payments can be made to disabled people in Scotland, England and Wales in lieu of social service provisions. The aim of direct payments is to give recipients more control over their own circumstances by providing an alternative to services provided by a local authority. Carers in England and Wales also have access to direct payments. Carers in Scotland do not have access to direct payments.

Direct payments are not a replacement for income and therefore do not affect any other benefits, including Carer's Allowance.

### *Scotland*

New national guidance was issued in 2007 (Scottish Government), which was designed to improve the take-up of what is now referred to as 'self-directed support' – this term is used interchangeably with 'direct payments'.

The guidance is based on best practice recommendations from national working groups, national research work, and the evidence from the Care Inquiry, and takes account of responses to a public consultation held from September to December 2006. It fulfils the recommendation made by the Scottish Parliament's Health Committee in its inquiry into the implementation of the Regulation of Care (Scotland) 2001 and the Community Care and Health (Scotland) Act 2002.

The guidance states, "a carer's assessment does not at present give the carer an entitlement to self-directed support in their own right. Its purpose is to clarify what they can do, what assistance they may need in order to be able to continue in their caring role, the carer's

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<sup>4</sup> House of Commons Library.

aspirations, and what assistance they may need planning for life balance beyond the caring role and to be able to keep well” (Scottish Government 2007a).

### *England and Wales*

In England (Department of Health 2003) and Wales (Welsh Assembly Government 2004) direct payments can be made to carers to allow them to purchase the services they have been assessed as needing to help them maintain their health and well-being. Carers may not receive a direct payment to purchase services to meet the assessed needs of the person they care for.

In addition, there is a facility available to allow young carers (16-17), who have chosen to undertake a substantial caring role for a disabled adult for a period and where the local council supports that decision. It may be more helpful to the young carer to receive a direct payment to allow them to arrange for carer services to be delivered in such a way as to minimise any disruption to their education that would result from their decision to care.

## **NATIONAL FUNDING FOR CARERS**

### **SCOTLAND**

In its Spending Review, the Scottish Government made a financial commitment of £1m/£3m/£5m respectively for the period 2008-09 to 2010-11, to expand support for carers, including carer training and local carer centres (2007b). It has been announced that the £9m will be provided to NHS boards across Scotland over the period to support the implementation of Carer Information Strategies (Scottish Government 2008b).

The Scottish Government has recently announced further funding for carers (2008c). In addition to the £9m outlined above, £300,000 will be used to fund two more national festivals for young carers, and £4 million will help deliver 10,000 extra weeks of personalised short breaks for carers a year by 2011.

However, the local government settlement has been and will be the main source of funding for local authorities to resource their carers support services. Scottish Government investment in local government will total £23billion in 2008-10. The vast majority of funding, including funding for carers services, will be provided by means of a block grant. It is the responsibility of each local authority to allocate the total resources available to it, based on local needs and priorities.

### **ENGLAND**

The UK Government issues an annual Carers Grant to every local authority in England. Spending by local authorities is monitored by the Commission for Social Care Inspection. Local authorities are able to determine locally how best to spend the Grant in order to deliver local and national priorities in their areas. The allocation for 2008/09 is £224 million, rising to £240m in 2009/10 and £256m in 2010/11.

Guidance to local authorities on the Carers Grant highlights the policy intentions (Department of Health 2008). This includes encouraging councils to develop ‘personalised, innovative and high quality carers services in response to local needs. This should be done in partnership with carers, relevant voluntary organisations, the local NHS and other statutory agencies’. The guidance also includes examples of good practice and a definition of a breaks service.

As part of the new Carers Strategy, financial commitments totalling over £255 million have been made for the period 2008-2011, which includes:

- £150 million to increase the amount of money provided by central government for breaks from caring for carers.
- £6 million to ensure young carers are protected from inappropriate caring and receive broader support.
- £61 million aimed at enhancing support to voluntary organisations and ensuring NHS and Social Care professionals focus on specific emotional and health needs of carers.
- £38 million to enable carers to be better able to combine paid employment with their caring role, and re-enter the job market after their caring role has ended through encouraging flexible working opportunities and increased training provision.

(Department of Health 2008c)

In addition, there is already a commitment to spend £340 million to support families of disabled children over the next three years, and £2.7 million a year to fund a new information helpline and website for carers (Department of Health 2008d).

## **ISSUES DISCUSSED AT THE ROUND TABLE DISCUSSIONS ON CARERS**

The Equal Opportunities Committee held two round table meetings on unpaid carers. Those giving evidence were:

- [Tuesday 25 March 2008](#) – Kathleen Bryson (Lighthouse Foundation), Claire Cairns (Coalition of Carers in Scotland), Fiona Collie (Carers Scotland), Norman Dunning (Enable Scotland), Stewart McFarlane (Perth and Kinross Young Carers Scotland), Jack Ryan (Crossroads Caring Scotland), Elizabeth Seaton (North Lanarkshire Carers Together).
- [Tuesday 7 October 2008](#) – Jane Kennedy (COSLA), Kathleen Marshall (Scotland's Commissioner for Children and Young People), Alan Swift (Scottish Court Service), Alexis Jay (Social Work Inspection Agency), and Lawrence Wason (Union of Shop, Distributive and Allied Workers).

The following section summarises the evidence that the Committee heard at its two round table meetings. Witnesses raised a wide variety of topics, for example, the UK Government's review of benefits, pensions and taxation, and other benefits issues that may impact on carers. However, this summary focuses mainly on areas that are devolved. The evidence is summarised under various broad headings.

### **SPECIFIC GROUPS OF CARERS**

Evidence at the round table meetings indicated that some groups of carers are less well supported than others. For example, carers of people with mental health difficulties may become isolated as a result of social stigma and therefore be reluctant to access services. Carers in rural areas may have support from outreach services but find that accessing centralised services is too costly.

#### *BME groups*

- Carers from black and minority ethnic communities need to have information and services provided in a culturally sensitive way.

- Social service and health providers need to develop a better understanding of BME communities in order to deliver the appropriate services.
- It is easier for some communities to access services if the service provider is from the same community. This can overcome language and cultural issues.
- In reference to research which shows that Asian men are three times as likely to be carers as young white men – services and support for carers needs to be built around such demographic changes and the changing role of care.

#### *Older carers*

- Older carers often have the most difficulty in accessing the services they need, and often the person they care for has to go into residential care.
- Despite the fact that the older population is increasing, very little support has been identified for older carers who will have changing and particular needs.

#### *Younger carers*

- Young carers can face isolation in the school environment, and it can be very difficult for them to identify themselves as carers. Support mechanisms would help reduce the stigma that is attached to being a young carer.
- One in four young carers will suffer from mental health difficulties at some point in their life.
- Moving and handling a cared for person can affect a child's physical health.
- Getting employment can be very difficult for anyone who's been a young carer. Work experience may be limited, and they may also be potentially lacking in qualifications, and they may still have a caring role which limits the hours they can work.
- Increased access to respite services for young carers is needed so that they can pursue their education or career.

### **ASSESSMENTS**

- One in five carers did not receive the services that their assessment showed they should have, the main service being respite.
- Carers have a right to an assessment, but it was argued they have no right to services after they have been assessed. It was suggested that there should be a duty on local authorities to provide such services. It is believed that in England and Wales there is a right to services following a positive assessment.
- Those over 65 should have a follow-up assessment every two to three years to ensure planning is in place for the carer and the person they care for.
- People tend to access services when a crisis point is reached. It is important to identify carers before such a situation arises.
- Good practice guidance is needed to improve assessment procedures for carers and provide more resources for respite. There should be monitoring and evaluation of those involved.

## **SUPPORT**

- About 40% of carers find that access to services is poor or that services do not meet their needs. This can have a knock-on effect on access to other services, for example if a carer cannot get cover to attend a GP appointment it can affect their health.
- In situations where a cared-for person will not accept services, local authorities need to be more creative about what they put in place.
- It was suggested that carers should get an annual health check at their local GP practice.
- It was asserted that some social workers have said that there is no point in carrying out assessments as there are no resources to provide what people need.
- The Scottish Government should fund a national helpline for carers in Scotland.

## **FUNDING AND FINANCE**

- The recommendations of the Care 21 report were encouraging, but there has been no shift with regard to additional funding. Funding is required to create an infrastructure to support carers.
- There is unclear guidance about charging for carer services.

## **LEGISLATION AND GUIDANCE**

- It would be good for the Government to promote the need to support carers in the workplace, irrespective of whether there is legislative provision for it.
- It was suggested the Scottish Parliament consider a promotion of equal opportunity for carers as in Section 75(1) of the Northern Ireland Act 1998 which states that public authorities should "promote equality of opportunity ... between persons with dependants and persons without."
- In England and Wales, local authorities are required to take account of a carer's desire to enter employment or education. This requirement does not apply in Scotland.
- Respite care varies between local authorities, and even within a local authority area. There is no uniform standard. It was suggested that a minimum standard should be introduced.
- The Parliament will have to take on board the judgement of the European Court of Justice which upheld an opinion that treating employees less favourably because of their association with a disabled person is unlawful. This decision ensures that UK disability discrimination law protects anyone who cares for someone who is disabled.

## **EMPLOYMENT**

- Investment in carers is worthwhile from a business perspective as it encourages loyalty from the carer toward the employer.
- Lack of local services, particularly respite provision, affects a carer being able to maintain employment.
- Carers who continue to work find that flexible schemes, such as Direct Payments, work better than trying to get a care package from local authorities. Care packages are often put together for working hours.

- Research into flexible working is needed to assess uptake, any barriers in accessing flexible working, ways of supporting employers and raising awareness of flexible working.
- There is a lack of specific support to help carers get back into work. Research shows that for some carers there is a lifelong impact on earning potential and career progression.
- Some employment support workers have negative attitudes towards carers and the type of work they are able to do.

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