

No Carer Written Off

A breakfast discussion with Rt. Hon. James Purnell MP, Secretary of State for Work and Pensions.

Chaired by Dr Philippa Russell, Chair of the Standing Commission on Carers.

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The Prime Minister's National Carers Strategy contained this commitment: "Within the context of wider welfare reform and the fundamental review of the care and support system, we must create a system of carers' benefits that is able to provide support where it is most needed and that can adapt to the wide range of needs that carers have." Welfare benefits are part of an interdependent system of care and support, as the inclusion of DWP funding streams in the Individual Budget pilots have evidenced. However, that system can feel disjointed to families who go through separate processes to receive different kinds of entitlements or budgets to meet their care and support needs. There would be considerable challenges to integration, not least the differing levels of devolution within the social care and benefits systems. This roundtable aims to provide some context to early thinking on welfare benefit reform for disabled people and carers, through considering the differences and commonalities in the issues facing families with care needs across the four nations.

Whilst benefits reform is a reserved issue, but needs to be considered in the context of differing programmes for adult social care reform being developed in the home nations. This roundtable will begin with brief contributions from experts in England, Scotland, Wales and Northern Ireland to set the scene. We shall then discuss the key issues.

The key questions for debate include:

- How might those social care systems interact with welfare benefits reform for disabled people and carers?
- Is it possible to move towards a more integrated care and benefits system that works for families with complex needs across the UK?

The social care system in all of the nations is moving towards offering greater choice and control to service users. We want to explore through discussion whether a similar approach would have merits for carers. Different mechanisms are being developed and piloted to help make this change.

In England, a Green Paper on adult care and support is due next year (**Alexandra Norrish** leads on this review for the DH). Meanwhile, the personalisation agenda encompasses a focus on choice and control, increased preventative work, unlocking social capital and making a universal offer of advice and information. The evaluation of the Individual Budget

(IB) pilot sites by IBSEN (team members included **Caroline Glendinning** and **Dr José-Luis Fernández**) has just been reported and is due to report specifically on the impacts on carers. IB involves pooling a number of council and DWP budgets into one allocation over which the service user or their carer has control. There are early discussions about widening the pooling of budgets to include NHS and welfare benefits allocations. The LGA (**Anne McDonald**) report, *Our Lives, Our Choices*, looks at one way of increasing coordination between council and DWP entitlements. LGA and ADASS (**Gary Vaux**) analysed a number of impacts of the current and proposed benefits systems on carers. The Princess Royal Trust for Carers (**Carole Cochrane**, **Alex Fox**, **Florence Burke**, **Ricky Devlin**) and Crossroads Caring for Carers (**Anne Roberts**) have developed a report called *Putting People First without putting carers second* which looks at personalisation from a carer's perspective.

In Scotland, the *Sutherland Report* in 2000 recommended that the costs of caring for older people should be split between living costs, housing costs and personal care, with personal care free in all settings. The Government is also currently implementing its Care 21 carers' strategy. **Professor David Bell** has researched the impact of personal budget approaches for Stirling University. **Neil Rennick** (Head of Older People) also joins us from the Scottish Government.

In Wales, the recently developed ten-year strategy, *Fulfilled Lives, Supportive Communities*, sets out a direction for social care as a core service helping communities to achieve the inclusion and empowerment of their citizens. **Stewart Greenwell** (Chief Officer for Social Care and Housing, Torfaen and President ADSS Cymru) and **Steven Milsom** (Dir Older People for WAG) are joining us for the discussion.

A key issue for carers is the balance between the responsibilities of the state and those of the family. At present there is no formal contract between state and family when it comes to care. This can lead to huge variations in how families perceive their responsibilities and rights. **Gerry Zarb** works on carers' rights issues at the Equality and Human Rights Commission. The decisions families make about providing care themselves are influenced both by social care entitlements and benefit entitlements. A number of different approaches are being taken, on an international level, to frame these responsibilities, with some placing more responsibility for caring for relatives on families, and some placing more responsibility on the state. Some lean towards nationally determined funding streams and some devolve resource allocations to local areas or even individual professionals in discussion with families. They are believed to have differing impacts on the uptake of employment and benefits by family members, particularly amongst women who are most likely to take on caring roles for parents in many societies. **Professor Caroline Glendinning** (Research Director, York University and Chair of the Social

Policy Association) and **Dr José-Luis Fernández** (Deputy director & research fellow, PSSRU, LSE) and have published research in this area.

A great deal of work has been done on the costs and benefits of different care systems. ILC (**James Lloyd**) has published recent reports on the impacts of caring on older carers and on models of financing social care. Demos (**Charles Leadbeater**) and ippr (**Lisa Harker**) have produced many reports on reform of the care system. Carers UK (**Imelda Redmond**) has demonstrated the costs and risks borne by carers through numerous influential research reports and has worked both on the carers' legislation that established the right to a social care assessment for carers, and with the DWP on carers' benefits and pensions. Carers at their recent Carers Summit had strong views on benefits reform. The Right Care, Right Deal coalition includes Carers UK and Counsel and Care (**Stephen Burke**) who have produced a number of reports looking at the care system for older people. CSCI (**David Walden**) notes in their review of eligibility criteria for social care in England that there have been "widespread calls for an adult social care system which places more emphasis on individual rights and national entitlements. Such entitlements might offer a set amount of funding for those with a particular level or type of need regardless of where they live (akin to a social security benefit)".

Apologies to those participants not included above – there were some later additions to the group.

Appendix – Examples of approaches taken by different countries*

France

A national system targeting the care of older people was set up in 2001 which provides for the allocation of a personal allowance. Assessment of the degree of needs and risks is made by a professional. A national scale allocates applicants to one of six groups, from the highest level of dependency to the lowest. The allowance is made in relation to a specific package of support services and depending on local supply. The tight conditions governing the allocation of the allowance (that is managed and largely financed by 100 French départements) and central planning for the départements are designed to prevent the growth of a 'grey market' in care services, and to ensure equity across the country. Nonetheless, debates

continue about postcode lotteries and whether a long-term care insurance scheme would be preferable as demand increases. The elaborate, centralised system for determining needs and risks, and the associated waiting lists, are seen by some as a means of deterring applications.

Sweden

Sweden operates a relatively generous welfare system. Ninety-seven percent of services are publicly funded from compulsory insurance and high taxes. It is seen as a citizen's right. Health and social care are formally considered as separate systems but have worked together for more than 25 years in care planning teams to ensure appropriate care for the individual.

Long-term care services are the responsibility of each of the 286 municipalities based on the principle (well supported by the public) that it should be the community, not the family, who cares for people needing support. Municipalities organise assessments for services along lines recommended by the Ministry for Health and Social Affairs but have a high level of autonomy to define and raise taxes for their own systems. There has been a downward trend in home help services and variation in provision between municipalities. However, recent research shows that levels of unmet need remain low despite shrinking service levels. Personal allowances for those under 65, who are severely and permanently disabled, are provided through the social security system.

Debate about equity and service quality continue and there are proposals for the development of national standards and closer collaboration between municipalities and the National Board of Health and Welfare.

Germany

Germany has a comprehensive, national long-term care insurance system which was reformed substantially in 1995 where public insurance covers most people and mandatory private insurance covers most of the rest (97% in all). The scheme is primarily to provide assistance in the home, and relatives can be employed with the allocation.

A standard assessment uses a national scale of risks and needs, including activities of daily living (ADLs). Benefits are either a care package or cash, or a mixture of the two. The social services element of the package are assessed by a local case manager making use of the completed medical assessment. Cash benefits have been particularly popular, and because they have been set at levels less than the cost of services, have helped to control the costs of the scheme. But, this has given rise to debates about the impact on women's employment and carers' rights; about the adequacy of the smaller cash sum; and about the impact on the development of a market for high quality professional services.

The Netherlands

The Netherlands has a statutory insurance scheme to cover the risks of long-term care, where the insurance is compulsory for everyone paying payroll tax and benefits are thus seen as a right. Policy supports the principle that the family is the carer of first resort. Benefits are offered as a package of services or (except for treatment or residential care) in cash as a

personal budget. There are seven broad categories of support – domestic help, personal care, nursing, supportive guidance, activating guidance, treatment and accommodation. A national, independent assessment agency is responsible for assessing eligibility for each kind of support, with local offices to carry out home visits or hold multi-disciplinary meetings. Assessments use a checklist of more than 100 items based on the World Health Organisation International Classification of functioning, disability and health. 'Indications' of eligibility are issued to successful applicants with a determination of hours and type of care which can be taken by the applicant to any local provider.

Responsibility for funding, developing and allocating home care was decentralised to the municipalities in 2007. People have less legal certainty about their entitlements and expenditure has gone down but, despite fears from some groups, there is no evidence as yet that services are fewer or worse. The Dutch system is transparent – citizens are readily able to find out how the system works and the lobby representing people using services is fully involved in its operation and debate about thresholds.

Japan

Since 2000, Japan has had a compulsory insurance-based long-term care system which mainly targets people aged over 65. Applicants are assessed by a doctor according to a national format which covers physical and mental health. According to the assessment, the applicant is allocated to one of seven categories (or none) ranging from 'in need of support' to 'in needs of nursing care assistance'. Neither the availability of informal help nor income is taken into account in the determination.

The eligibility framework was revised in 2006 because of spiralling costs and a new package of preventative services was introduced. Questions remain about the financial viability of the scheme.

**Extract from [Cutting the cake fairly CSCI review of eligibility criteria for social care](#), CSCI November 08 available at www.csci.org.uk/professional*

The Princess Royal Trust for Carers – What do we do?

Our mission is to make a positive difference to the lives of carers. We do this in partnership with the network of The Princess Royal Trust carers' centres, statutory and voluntary organisations, and by acting independently in the interests of carers throughout the UK.

We work in partnership with the network of carers' centres, as well as with other carers' organisations, to meet the challenges carers face. The key to our work is to provide a range of flexible services at a local level through the network of carers' centres, including influencing practice. We can only do this working in partnership with organisations that provide and deliver high quality services.

We use our considerable experience and the expertise and knowledge of the network to pilot new and more flexible ways of delivering services, actively demonstrating how these can be used in different parts of the country.

We also work with other agencies including the health service through hospitals and GP surgeries, to achieve our ends. We use research and the data held by the network on carers to make the case for carers' services and lever change.

Crossroads Caring for Carers – What do we do?

We have two main roles – the first is to support the network of Crossroads schemes so that they are able to develop and deliver services to carers and their families. This support includes advice and guidance on service issues, policies and procedures, insurance, training and quality assurance.

Our second area of work is to make links with other organisations and the government in order to strengthen support for carers. We aim to broker national partnerships that result in more service delivery at a local level and to contribute to the development of legislation and policy that impact on Crossroads schemes and on carers.

In the first year of operation in 1974, Crossroads supported just 28 families. Today Crossroads Caring for Carers consists of approximately 140 member schemes throughout England and Wales. Over 4.6 million care hours are provided every year to more than 35,000 carers – The equivalent of over 525 years of care.

Every scheme provides practical support where and when it is most needed – usually in the home. A trained Carer Support Worker will take over from the carer to give them 'time to be themselves'. We talk to the carers about how often they would like us to visit, how long the visit should be and at what time they would like our support provided. They then have 'time' to use as they wish – to see friends, keep appointments, study, read or even just to sleep. Many of our schemes provide additional services including young carers projects, holiday play schemes for disabled children and care for people who are terminally ill.

A Crossroads service is about giving time - improving the lives of carers by giving them a break from their caring responsibilities. Our aim is to provide a reliable, tailored service, for each carer and the person they care for. We have schemes in most parts of England and Wales, which provide a range of services.

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