

# Achieving recognition and support for carers

November 16<sup>th</sup> 2011: Conference Report

A recently published CIRCLE report, *New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme* was launched at the 'Achieving Recognition and Support for Carers' conference, which attracted over 180 delegates from across the UK. Participants had an opportunity to hear the perspectives of national policy makers and leading practitioners in carer support. During an inspiring and successful day, delegates discussed many aspects of carer health and well-being support and raised issues in the round table discussions that were fed back to the Department of Health's *Caring for our future* engagement process.

## Keynote speakers



The day, hosted by CIRCLE, University of Leeds, was chaired by **Imelda Redmond CBE**, Director of Public Affairs at Marie Curie Cancer Care (and formerly Chief Executive of Carers UK).

Imelda stressed the importance of discussing policy implications of the findings from the national evaluation of the Carers' Strategy Demonstrator Sites, and welcomed the opportunity this event presented to provide feedback directly to the Department of Health for the forthcoming White Paper on Health and Social Care.

The first address was given by **William Vineall**, Deputy Director for Social Care and Policy Legislation at the Department of Health, who spoke about the White Paper engagement exercise *Caring for our future*. He highlighted one of the emerging messages from the engagement exercise – that the current system of carer support does not incentivise preventative approaches to social care. He asked delegates to give serious consideration to how this could be achieved whilst upholding quality as a guiding principle for care and within a marketplace that has a greater focus on quality as opposed to cost. He also emphasised the importance of meeting the challenge of



increasing demand and higher expectations, and the desire for wider economic growth, by building the capacity and capability of those who support unpaid carers.

**Professor Sue Yeandle**, Director of CIRCLE and Principal Investigator for the National Evaluation of the Carers' Strategy Demonstrator Sites programme outlined some of the key findings and policy messages from the evaluation. She explained that the Demonstrator Sites programme provided evidence that low-cost support at appropriate points benefits some carers, and that,



in some circumstances, well-being support can be successfully delivered by trained, non-clinical staff. The Demonstrator Sites had additionally shown that placing carers' champions in GP practices and hospital wards, co-ordinated by voluntary sector agencies, worked to improve carer support. The evaluation also illustrated that services need to be accessible and responsive at different points in a carer's role – at the start, at times of stress, and when caring is long-term or intensive.

Lively question and answer sessions followed both of the first two speakers. Contributions covered a



variety of topics, including the importance of developing comprehensive services at a local level to deliver high quality services, and the need for long-term commitment to tackling the challenges facing the health and social care system.



The morning session concluded with an inspirational talk by **Dame Philippa Russell**, who, as Chair of the Standing Commission on Carers, spoke about the challenges and new opportunities of delivering quality services to carers. She reminded the audience how important it was to make the most of current opportunities to ensure carers become 'strategic partners' in delivering services, and spoke about the importance of empowering carers by sharing information with them.

**Summary of Key Findings:  
National Evaluation of the Carers' Strategy  
Demonstrator Sites Programme**

The Demonstrator Sites showed that working together, NHS, local authority and voluntary sector staff can develop creative, innovative, personalised carer support. Evidence from the sites also highlighted that flexibility and responsiveness to local circumstances is extremely important. Some of the key findings from the evaluation of the sites are described below.

**Impact on Carers**

- Sites' approaches were effective in targeting some of the neediest carers.
- Unmet needs were often addressed, and carers found services beneficial.
- Flexible and personalised breaks are life-enhancing for many, and can prevent 'burn-out' or health deterioration.
- Health checks led to sustained self-care and healthier behaviours among some carers.
- Signposting to further services worked well for some but should be carefully monitored for suitability and effectiveness.

**Partnerships**

- Multi-agency support can be implemented without disruptive effects on existing workloads, but setting this up can be time-consuming.
- Voluntary sector agencies play a key role and may bring valuable additional expertise.
- Carer awareness training may be needed, especially for some NHS staff.
- Different organisations can lead different developments.
- Careful attention needs to be taken in planning service integration / development; special effort is needed to engage some GPs.
- The DS programme leaves a valuable legacy of documentation and tested processes on which to build.

**Engaging and Involving carers**

- A focus on local needs and circumstances can help target services to those in greatest need.
- NHS-led initiatives, developed in partnership, offer good scope for extending and improving carer support.
- Careful attention needs to be taken not to neglect male and younger carers.
- Effective carer support relies on multi-agency partnerships which go beyond the health and social care system.
- Involving carers means including them in project planning from the start, offering them training and support and drawing a diverse range of carers into projects.

**Policy Recommendations**

*From: New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme*

1. In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together to develop and deliver effective support for carers, in partnership, should be strengthened.
2. Local carer support partnerships should involve a diverse range of carers in service development.
3. In delivering support to a wide range of carers and reaching carers not already in touch with services, local partnerships should work flexibly, and sometimes on an *ad hoc* basis, to engage carers in specific target groups.
4. Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs.
5. Portfolios of carer support need to be agreed locally between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate.
6. Hospitals should routinely provide mechanisms to identify and support new carers, focussing their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them.
7. Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances.
8. All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and well-being and equipped to advise on how a carer can access a health and / or well-being check.
9. All relevant organisations should regularly offer carer awareness training to their staff.



In the afternoon, delegates took part in seven 'round table' discussions, covering six different topics.

Each discussion was facilitated by a chairperson, and debate and informative exchanges were stimulated by short presentations from invited contributors. CIRCLE would like to thank those who contributed to this element of the day:



**Jill Akroyd**, Commissioning Manager, Community Wellbeing Team, Hertfordshire County Council.

**Tim Anfilogoff**, Head of Community Wellbeing, Hertfordshire County Council.

**Hilary Arksey**, Freelance Researcher and Consultant.

**Alan Ashton**, Chief Executive, Princess Royal Trust for Carers, St Helens Carers Centre.

**Caroline Bernard**, Policy Manager, National Skills Academy.

**Marie Casey**, Deputy Chief Executive, Care for the Carers.

**Clare Cotter**, Joint Planning and Strategic Commissioner - Carers, Devon PCT.

**Denise Coy**, Expert Adviser to the Demonstrator Sites Programme, 2009-2011.

**Fiona Cutts**, Project Manager "Who Cares?" Project, South Essex Demonstrator Site, 2010 – 2011.

**James Drummond**, Lead Officer, Integrated Carer Services, Torbay and Southern Devon NHS Care Trust and Expert Adviser to the Demonstrator Sites Programme, 2009-2011.

**Liz Fenton**, Chief Executive, Princess Royal Trust for Carers and Expert Advisor to the Demonstrator Sites Programme, 2009-2011.

**Carla Fourie**, Associate Director for Social Care and Partnerships, South Essex Partnerships Trust.

**Clare Hammerton**, Short Break Coordinator, Suffolk County Council.

**Emily Holzhausen**, Director of Policy and Public Affairs, Carers UK.

**Nick Kennedy**, Strategic Project Development Director, Enterprise4All.

**Jill Lockwood**, Carers Strategy Officer, Kirklees Council.

**Richard Manby**, Head of Development, Slivers of Time Systems.

**Ailsa Martin**, The Princess Royal Trust, Sunderland Carers' Centre.

**Joanna Ridley**, Carers Development Manager, Swindon Borough Council.

**Anne Smyth**, Deputy Chair, Standing Commission on Carers.

**Karen Timperley**, Joint Strategic Commissioner- Carers, Camden Council.

**Carol Watson**, Service Manager (Under 65's and families) Bristol City Council.

**Mandy Whittaker**, Expert Adviser to the Demonstrator Sites Programme, 2009-2011.

## Report back: Round table discussions

### Delivering flexible and personalised breaks for carers

Delegates discussed that:

- For carers offered a breaks service, having dedicated support workers who can help them look at the various 'breaks' options available has been invaluable.
- Being offered a free choice without any support is sometimes daunting. Without this support, carers may not take up the offer of a 'break'.
- The ability to offer a 'break' which enables a carer to access something that is important to them, which may cost less than a 'standard' break or service, can often have a positive impact on the carer.
- The definition of a 'break' needs to be flexible. One delegate cited the example – described by the carer as 'life-changing' – of paying the travel insurance costs of a person being cared for, enabling the carer and the person cared for to go on holiday together.
- Involving carers in the development of breaks services means that services are more likely to be tailored to carers' needs and can also help to identify whether the carer or the person being cared for should be the 'recipient' of the break.

### Supporting carer health and well-being using health checks

Discussion points included:

- Health checks for carers are important for a number of reasons; they enable carers to maintain and improve their own health and help them to sustain their caring role for as long as they want or need to.
- The well-being elements of health checks are often as (if not more) important to carers as the physical health elements.
- Although a holistic approach is preferred, managing expectations is also important. Carers in the Demonstrator Sites expected different things from their checks depending on where they were delivered (across the sites, checks were offered in a range of locations including carers' own homes, pharmacies and GP practices).
- Encouraging carers to take up the offer of health checks is challenging for a range of reasons; it is particularly difficult to encourage some carers to attend - for example, those caring for more than one person and those new to caring.
- Carers reluctant to access health checks services may nevertheless benefit from a discussion about their needs - for example, in preparation for the discharge from hospital of the person they care for. Carers may not want or need a full health check, but often value knowing where to go for support and what help may be available.

## The benefits of supporting carers in hospital settings

Delegates suggested that:

- Providing information to carers can be done very effectively by people who are not health or social care professionals, a process that in turn can help ease the workload of those who are.
- Providing information to carers builds the confidence of both carers and the person being cared for, enabling them to find out about choices available and make informed decisions about options.
- It is vital to continue to engage hospital staff, recruit carers' champions, utilise volunteers and provide training for all those who may come into contact with carers. Some delegates felt carer awareness training needed to be mapped nationally.
- Other delegates proposed an appropriate data monitoring system to demonstrate the value and benefits of supporting carers in hospital settings. They felt this should be done through indicators linked to medical conditions, with this monitoring integrated with systems currently in use in hospitals. Delegates hoped the Department of Health would consider investing in these types of services.

## Working effectively with GPs and GP practices

Discussion points covered:

- Delegates felt that encouraging GPs to identify carers is still a challenge in some localities.
- They noted that many different methods have been tried, with some success, in various parts of the country. Methods mentioned included: employing dedicated workers to work in or with GP practices; developing the concept of a 'core offer' enabling all carers to expect the same basic package of support, advice and information, sometimes with a 'carer's passport' to hand to the GP to receive specialised support; offering free training to GPs; publishing a 'league table' of the number of referrals made by each GP practice; encouraging GPs to display a notice board specifically for carers; and providing training sessions to all staff within a GP practice, covering topics such as identifying carers, understanding carers, and referring carers.
- Carer involvement in forums can also be a positive way of encouraging GPs to be interested in the lives and needs of carers.
- Methods of signposting carers are important too; prescription pads and leaflets are both useful approaches used in some GP practices.

## Meeting the training needs of carers

Delegates' views included that:

- Developing generic training sessions for carers can be challenging because of carers' complex needs and requirements.
- Young carers are an extremely important group; if the needs of young carers are not addressed, there will be considerable costs later on.

- Although technology is not necessarily the answer for everyone, it is currently under-utilised for training opportunities for carers.
- Delegates who had been involved in running courses for carers noted that demand for alternative care (or for funding for alternative care) is usually quite low, although providing the option of alternative care is important for socially excluded carers.
- The term 'training' is a barrier for some carers. While it is difficult to find an alternative term which suits all needs, advertising training as a 'course' or as 'support' may be more appropriate.
- Ideally, carers should be offered a menu of services by organisations which not only address training specifically aimed at carers' needs but also offer opportunities to access mainstream, universal services.
- Rolling programmes can help carers to access training if regular attendance is problematic for them.

## Enabling carers to fulfil their employment potential

Delegates discussed that:

- Since helping someone return to work is often much harder than supporting a carer to remain in work, attention needs to be paid to supporting carers in the workplace, as well as to supporting those who wish to enter or re-enter the workforce.
- Carers need advice about how to obtain paid employment. Delegates felt young carers especially would benefit from better careers and advice services.
- Mentoring services for young carers who have been absent from school due to caring can help them in their caring role, as can advice and guidance provided in schools about what jobs are available. Delegates noted however that such advice services are increasingly reliant on mentors from the voluntary sector.
- One model which had worked well in a London Borough was involving successful local business owners to help others from the same communities get work, which delegates thought should be tried elsewhere.
- Carers may feel guilty about taking time away from work due to caring responsibilities and often do not want to be treated differently. They want their work colleagues to be understanding and for the company to support carers as employees.



## Closing Plenary



The final session of the day was delivered by Anne Roberts, Chief Executive of Crossroads Care. Speaking about 'voluntary sector perspectives on carer health and well-being', she stressed the importance of forming strong partnerships to achieve real change. Commenting that the Demonstrator Sites programme had highlighted the voluntary sector's crucial role in delivering services for carers, she stressed that this issue must be kept in mind by those designing and commissioning services. She reminded delegates that 'in reality, it doesn't matter to people whose name is over the door of an organisation when they are first identified as a carer – they need empathy and understanding at the first point of contact'.

## Feedback

The CIRCLE team would like to thank all those who attended and participated in the conference for making it such an informative and thought-provoking day. A few comments drawn from the highly positive feedback about the conference are provided below.

*I thoroughly enjoyed the whole day, thank you. The information was priceless. We need more regular local conferences!*

*I thought the whole day was very well organised – very useful and informative and genuine speakers.*

*Great day - I was able to meet like minded people and was able to gain confidence in the areas of weakness.*

*There seemed to be a real buzz and exchange in breaks as well as in sessions!*

### More information about CIRCLE

**CIRCLE**, the **Centre for International Research on Care, Labour and Equalities**, undertakes a wide range of policy-oriented and theoretical work on the themes of care, work, social inclusion, inequalities and diversity. CIRCLE's work builds on a strong base of studies on these topics, established through Sue Yeandle's *Gender and Employment in Local Labour Markets* programme (2003-6); the *Carers, Employment and Services study* (2002-7, conducted in partnership with Carers UK); and the ESRC *Care and Values Research Group* (CAVA, 1999-2005) directed by Fiona Williams. All of CIRCLE's research considers the relevance of these themes for public policy at international, national and local scales.

Directed by **Professor Sue Yeandle**, **CIRCLE comprises a strong team of researchers skilled in a wide range of social research methods**, working in well-established partnerships both within the academic world - across many countries - and with many organisations in the public and voluntary sectors and in business and industry.

### CIRCLE publications

**New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme**

<http://www.sociology.leeds.ac.uk/circle/circle-projects/national-carers-strategy-demonstrator-sites.php>

**Carers, Employment and Services reports**

<http://www.sociology.leeds.ac.uk/circle/publications/ces-reports.php>

**Developing a clearer understanding of the Carer's Allowance Claimant Group**

<http://www.sociology.leeds.ac.uk/circle/circle-projects/completed-projects/carers-allowance-claimant-group.php>

**(Forthcoming) Training and Supporting Carers. The National Evaluation of the *Caring with Confidence* Programme**

<http://www.sociology.leeds.ac.uk/circle/circle-projects/evaluation-of-the-caring-with-confidence-programme.php>

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