Summary

New Approaches to Supporting Carers’ Health and Well-being: Evidence from the National Carers’ Strategy Demonstrator Sites Programme

The National Carers’ Strategy Demonstrator Sites (DS) programme was developed by the Department of Health (DH) as part of the commitments made in the 2008 National Carers’ Strategy. 25 sites were chosen to develop innovative services for carers focussing on three areas: breaks; health checks; and better NHS support. Each site had a pilot lasting 18 months up to March 2011.

Evaluation of the pilots was conducted by University of Leeds who published a report in November 2011. This is a summary of that report which can be accessed: http://www.sociology.leeds.ac.uk/circle/circle-projects/national-carers-strategy-demonstrator-sites.php

General findings and recommendations (page numbers in brackets)

1. Most carers supported by the pilots felt they benefitted from the kinds of services offered, finding them a suitable way of meeting some of their otherwise unmet needs. (126)
2. Pilots advised that involving carers in the design, delivery and evaluation of services made these more effective. (69)
3. In developing carer support, voluntary organisations play a key role and may provide expertise not available elsewhere. However, voluntary staff should not be overburdened and their roles/activities adequately resourced. (128)
4. Local partnerships should consider resourcing local voluntary sector organisations to deliver well-being checks for carers. (132)
5. Local carers’ organisations intelligence on carers and support needs should be valued and discussed when projects are designed. (128)
6. Many Primary Care Trusts (PCTs) and local authorities felt that carers preferred services delivered through voluntary sector agencies, whilst some voluntary organisations felt that carers’ concerns about “official” organisations might be transferred to voluntary groups. (42)
7. Face to face and word of mouth seemed to be more effective than raising awareness of services amongst carers than advertising/marketing. (67 &129)
8. Pilots found avoiding the term ‘carer’ in marketing materials was important. (Exec Summary)
9. Pilots had some success in reaching carers combining work and care. Across all sites, 60% of carers were people of working age and of these a third were carers in paid employment. (75)

10. Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification. (132)

11. 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 how to signpost towards a health and / or well-being check. (132)

**Breaks pilots - features**

The personalised breaks offered by pilots can be categorised into eight main types: carers’ holiday breaks; practical help in everyday life; well-being support / services; training for the caring role; work-related training; training for other skills; and funding for the purchase of equipment and domestic goods. (13)

In Sunderland’s pilot, cash payments to carers were administered by the Carers’ Centre to avoid the bureaucracy of the local authority (42). Derby’s pilot created an electronic system for GPs to refer carers to the breaks service which included a ‘feedback mechanism’ informing the GP of the outcome of the referral (45).

There is a good summary of how carers perceive the benefits of different types of breaks/services offered on pg. 91. Services covered include respite, well-being services, practical support, training and equipment.

39% of carers surveyed in the pilots had not previously taken a break from their caring role at all, and a further 41% had only ever taken a break of a few hours, and not overnight. (80)

The Breaks sites were particularly successful at engaging with carers of people with dementia (38% of all carers supported were carers of people with dementia, compared with 18% in Health Checks and 23% in NHS Support sites, indicating that breaks may be more valued by carers of people with dementia (58).

**Breaks pilots - results**

1. Pilots found that the number of carers accessing alternative care was lower than expected. The Tower Hamlets pilot, which had the highest number of carers accessing alternative care, allowed carers to pay family members or friends to ‘cover’ for them (or offer suitable support) rather than use an agency, care worker or personal assistant (56).
2. The most common ways carers advised how they became aware of the breaks’ service was through a Carers’ Centre (32%) and then social services (20%) (80).

3. 3% of working age carers started a new paid job after starting their breaks, whilst an additional 3% increased the number of hours they worked. Another 16% had either applied or were considering applying for a job (85).

4. 49% of carers advised that a break had improved the balance between caring and other relationships (85). 29% of carers said a break improved the care that they gave and 42% said it improved their ability to take care of person they care for, and 39% said it had improved the way they look after their health (86).

5. Over four months, 39% of carers who had not received a break showed a significant deterioration in their well-being, compared to 29% who had received a one-off break and 24% who had received on-going support. (85).

6. Torbay’s pilot used the GHQ-12 (General Health Questionnaire) before and after providing the service to carers and reported a highly significant reduction in distress amongst carers during the time they received the service, as well as highly significant reductions in distress for carers overall (113).

7. In the East Sussex pilot, care co-ordinators advised that in 90 of 203 cases, breaks had meant emergency alternative care had been avoided (109).

8. Sunderland’s pilot suggest that by providing a break to carers in receipt of intensive home care packages (of more than 10 hours a week) permanent admission to care within the next two years can be avoided, however this was only an 18 month study with a small sample of carers. (116)

Health Check pilots - features

Physical health checks included:
blood pressure; blood sugar / glucose levels; Body Mass Index (BMI);
cardiovascular check; cholesterol; current medications / conditions; family medical history; peak expiratory flow-rate; pulse rate; symptoms checklists; and urinalysis through multi-stix. Most sites used nurses to carry out the physical examinations although Trafford delivered them through the Carers’ Centre and some were done at home. (22)

Well-being checks often included:
considering the caring situation; exploring opportunity for breaks and social support; exploring ‘life-style’ including work, education, leisure and social activities; establishing environmental or safety concerns; and providing financial advice. It was more common for these to be conducted by people other than nurses and outside of traditional NHS settings. (23)
Devon developed a partnership with St John’s ambulance which was effective in delivering health checks and engaging carers (45). Camden’s pilot successfully identified young carers by working with schools, colleges and youth centres (64). Ethnic minority groups preferred having the option of checks delivered away from GP practices, health checks were also provided at other local community centres (69).

Many pilots found GPs a particularly hard group to engage because (46):
- Many GPs prioritise needs of patients and not carers.
- GPs lack resources to support carers
- GPs feared increased workloads if they began to support carers

These points indicate that GPs need to know the comparably poor health carers experience making them more likely to become patients and how this impacts upon their workload.

**Health Check pilots - results**

1. The Tower Hamlets site reported that the level of mental health need identified using the GHQ-1226 was higher than anticipated. (23)
2. Four months after a health check, 28% of carers surveyed felt the way they looked after their own health had improved; 23% were taking more regular exercise (87). Health and well-being checks lead to sustained self-care and healthier behaviour for some carers. (126)
3. 80 of 117 carers (68%) who had received a health check in Camden scored improved well-being on the WHO-5 index, while a comparator group of 101 carers showed no significant improvement over the same time period. (113)
4. Tower Hamlets reported that health checks identified 66% of carers with pre-high, high or low blood pressure, who were then referred for preventative support or further treatment. (112)
5. Devon reported that 66% of the health and wellbeing checks (1,644/2,510) led to further NHS referrals including GP and practice nurse appointments, phlebotomy, stop smoking service, a screening programme, health trainers, community nursing, check-ups for dentistry, opticians, and audiology. (112)
6. By far the two most common ways carers advised how they became aware of the health checks’ service was through a GP (42%) and Carers’ Centre (25%). (80)
7. Devon’s pilot delivered the highest number of health checks using events, working with clinical staff, existing registers, promotions in the local media, leaflets, website promotions, publicity in GP practices and specific clinics. (66)
Six main approaches were taken: hospital based support; primary care based; befriending and peer support; awareness training for NHS staff; improving information about and for carers; and Carer’s Assessments. Five sites developed a carers’ charter or carers’ policy for their local organisations / trusts. (27)

West Kent used voluntary sector workers to conduct assessments on the council’s behalf which became a shared health and social care assessment. Services offered included personal budgets and adapted ‘Caring with Confidence’ training (30).

Bolton’s pilot led by the NHS Foundation Trust developed a carer awareness training course which is now delivered as part of their mandatory induction for all new staff (37).

In hospitals, successful practices included ward-based initiatives, co-ordinated and led by voluntary sector agencies, which involved nurses, doctors and health care assistants and made services and support available to carers in the hospital setting. (127)

In Halton and St Helens, a Carers’ Centre staff member was based in the hospital with an NHS e-mail address and this improved co-ordination and responsiveness to the carers’ needs (p43).

There is a good summary of how carers perceive the benefits gained from the NHS Support Sites on pg. 95. This includes comments on the effects of awareness training of staff, befriending support, hospital based support and assessments.

**NHS Support Pilots - Results**

1. Pilots offering hospital based carer support reached large numbers of carers and some sites had difficulty meeting the high level of demand for this service, particularly the benefits advice service offered in Halton and St Helens. Demand for Primary Care based carer support and the befriending and peer support services was more variable (31).

2. The two NHS Support sites which supported the highest numbers of carers (Halton and St Helens, Hastings and Rother) both attempted to identify carers in hospitals and GP practices by:
   - Ongoing awareness training on what a carer is and how to identify them
   - Liaison workers having a visible presence in wards and GP practices
   - Feeding back to GPs/hospital staff about outcomes of referrals to demonstrate the benefits
   - Using carer registers
This approach appeared to be relatively cost effective, as the total funding allocated to these two sites was relatively low compared with other NHS Support sites, as was cost per carer supported. These techniques, however, required ongoing staff training and support and some staff questioned the long term sustainability of this approach (62).

3. A survey of 77 carers who received support from the West Kent NHS Support site concluded that there had been five cases of avoided Accident and Emergency Admissions and a further four cases of reduced need for emergency replacement care (Pg. 109).

4. Halton and St Helens pilot had a hospital based income maximisation officer providing benefits advice which led to 233 carers receiving £1.3 million of benefits. (111)

Gordon Conochie, Policy & Parliamentary Officer: gconochie@carers.org

17/01/12