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CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR & EQUALITIES

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Report Summary

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

This report summary presents key findings of the national evaluation of the Department of Health's Demonstrator Sites (DS) programme which aimed to improve carers' health and well-being, in line with a commitment made in the 2008 National Carers' Strategy.

The evaluation study was conducted by CIRCLE at the University of Leeds and aimed to:

- **map and assess the effectiveness of specific initiatives**
- **examine their impact on carer health and well-being**
- **outline the cost of initiatives**
- **assess the level and nature of carer engagement in planning, delivery and evaluation of the programme.**

A mixed methods approach was adopted comprising:

- **analysis of monitoring data**
- **case studies of selected sites**
- **surveys of participating carers**
- **interviews with staff delivering the programme**
- **documentary analysis.**

Key Findings

- Staff in the NHS, local authorities and voluntary sector organisations, working together in the 25 Demonstrator Sites, developed a wide range of creative and sometimes innovative approaches which worked flexibly for carers and offered them personalised support. They showed the value of services which are accessible at key points in the carer's journey, especially when caring first arises, at points of change or stress in their caring situation and on a regular basis when caring is long-term and intensive.
- The sites demonstrated that multi-agency support for carers can be developed without an unduly disruptive effect on the workloads of staff in the health and social care system. A flexible approach to job content and professional roles is needed, however, and additional training was required for some staff. To encourage GPs to engage with carer support, some sites needed to adopt special approaches and invest considerable effort.
- Voluntary sector organisations played a key role in developing carer support and sometimes provided expertise not available elsewhere. There was some evidence of voluntary sector staff experiencing workload pressures in cases where their roles and activities were not well defined or were inadequately resourced. Local carers' organisations sometimes felt their previous investments in building local intelligence about carers and their support needs were taken for granted or not fully valued.
- Carer identification, engagement and involvement required strong multi-agency partnerships supported by additional networks, within and beyond the health and social care system. In engaging carers, some agencies relied heavily on word-of-mouth and face-to-face contact. The sites showed that good practice in involving carers means including them in project planning from the start, ensuring they have adequate support and training, drawing on a diverse range of carers, and being attentive to, and flexible about, challenges in involving them. NHS Support sites identified many carers in primary and secondary care settings who had not previously received any support.
- Most carers supported by the DS felt they benefitted from the services offered. The sites adopted approaches which worked well in targeting some of the neediest carers. Flexible and personalised breaks support was shown to be life-enhancing for many carers. There was evidence that this had the potential to prevent carer burn-out / health deterioration and sustain carers in their caring role. Health and well-being checks led to sustained self-care and healthier behaviour for some carers.
- Sites were able to show a wide range of ways in which cost savings may potentially be made through carer support. The relatively modest costs of providing carer support indicate that continuing to expand support for carers, especially when caring begins, for those with intensive or long-term caring roles, and when carers experience strain, can be a financially sustainable approach.

Foreword

Carers are the backbone of the English health and social care system and finding the best ways of offering them support has never been more important.

This report draws attention to the many ways in which staff in the NHS and in local authorities can work together with voluntary and community organisations to help carers maintain their own health and well-being.

The innovative work carried out in the 25 National Carers' Strategy Demonstrator Sites in localities across England brought carers together with local community organisations in NHS or local authority led partnerships. It provides every GP practice, hospital, and local authority in England with ideas, examples and inspiration in their search for the most efficient and effective ways of identifying, recognising, valuing and supporting carers in their local area.

Enabling local agencies to work together to meet carers' diverse and varied needs is high on the agenda of the Coalition Government and this report on the work undertaken in the Department's Demonstrator Sites programme provides information which should inform and guide decision-making at every level. The findings of the evaluation study reported here will be carefully studied to ensure the learning from this important work feeds into the Department's autumn 2011 engagement exercise on the Future of Care and Support and informs the White Paper on Care and Support, due to be published in spring 2012.

Paul Burstow MP

Minister for Care Services

Introduction

The National Carers' Strategy Demonstrator Sites (DS) programme was developed by the Department of Health (DH) as part of the commitments made in the July 2008 National Carers' Strategy 'Carers at the Heart of 21st Century Families and Communities' (HMG, 2008). The programme, delivered across England, comprised 25 partnerships, each led by either a local authority or a Primary Care Trust (PCT) working in partnership with other local agencies. With a delivery period of 18 months, each Demonstrator Site was expected to develop new and innovative services for carers, or to extend existing provision if effective arrangements were already in place. The programme focused on three areas of support to improve carers' health and well-being: carers' breaks; health checks; and better NHS support.

- Twelve Breaks sites were awarded DS funding which aimed to measure the quality and effectiveness (including cost effectiveness) of a range of new approaches to offering breaks to carers.
- Six Health Checks sites were funded to deliver annual health and / or health and well-being checks for carers.
- Seven NHS Support sites received DS funding to explore ways of providing better support for carers in NHS settings.
- During the lifetime of the DS programme support was given to 18,653 carers.

The aim of the programme was for sites to develop and enhance their services and support for carers and, where possible, to measure the quality and effectiveness (including cost effectiveness) of the new provision. Particular emphasis was placed on demonstrating opportunities for the NHS to offer better support to carers. The objectives for the overall DS programme are set out on the opposite page.

Objectives of the Demonstrator Sites Programme

- Establish demonstrator sites involving: carers and people they support, social care, housing, health, the third sector, the private sector and others to develop improved support for all carers.
- Evaluate effective engagement of carers throughout the planning, delivery and evaluation of each demonstrator site.
- Create an effective learning and support network for the demonstrator sites in order to support their development.
- Establish a rigorous evaluation of the project as a whole, which will add to the current evidence base and identify what benefits can be achieved for all carers in each of the three strands of the project.
- Provide evidence about the effectiveness of specific policies or initiatives to better support all carers.
- Provide any evidence that early investment in supporting carers results in savings later as carer health, and that of the person they support, is maintained or improved.
- Disseminate and share widely the emerging learning as well as a final report from the demonstrator sites to encourage the adoption and dissemination of benefits within the social care, health and wider community.
- Establish a knowledge base to support local authorities and PCTs in their commissioning and performance management of services to support carers and the people they support.

Source: DH (2009).

Innovation and effective practice

For the duration of the DS programme, the 25 sites planned and delivered a large volume of services and support for carers in new settings, via new or extended partnerships. Most sites developed new delivery approaches or other new ways of working and initiated at least some new services which were innovative. Many sites also made significant changes to existing provision which staff considered made a positive difference to carers.

Almost all sites worked with partners across the health, social care and voluntary sectors, and some also engaged with other agencies, including private sector organisations. The role of the partner agencies varied by type of site and the specific activities offered.

The breaks provision included: specialised short-term respite for carers of people with dementia / mental ill-health; imaginative use of alternative care in the home; and an extremely flexible approach to the delivery of personalised breaks (based on carers' own needs). The key innovative approaches adopted by these sites are summarised below.

Carers' Breaks: key innovations adopted by sites

- New ways of providing information and advice (Derby and Hertfordshire).
- Support with practical activities in the home (Suffolk).
- One-off payments for equipment and domestic goods (Liverpool and Suffolk).
- Training for carers covering the caring role, work-related and other skills (Suffolk).
- New ways of communicating with, or providing services to, carers using on-line breaks booking systems or carer websites (Hertfordshire, Suffolk, Warwickshire).
- Introducing carer self-assessment (new in the Liverpool site).

Sites providing health checks offered physical health examinations and health and well-being checks sometimes combined but in other cases delivered separately. Some sites experimented (with some success) with delivering these using non-clinical staff and / or staff based in voluntary organisations. The key innovative approaches adopted in the Health Checks are presented below.

Health Checks: key innovations adopted by sites

- Delivering health and well-being checks to carers using staff based in voluntary sector or carers' organisations, rather than health professionals (Camden[1] and Trafford).
- Delivering health checks in a choice of venues, including in carers' own homes (Devon, Northumberland, Redbridge, Trafford).
- New delivery arrangements and content, including checks to assess well-being in the physical health checks offered to carers (Camden, Northumberland and Redbridge).

NHS support services offered new ways of supporting carers in hospital and primary care settings. They included befriending and peer support activities, awareness training for staff, and improving information, documentation and access to Carer's Assessments. The key innovative approaches adopted by these sites are summarised below.

NHS Support: key innovations adopted by sites

- Providing direct carer support in an NHS Acute Trust (Halton and St Helens).
- Providing staff to work directly with carers in GP practices (Hastings and Rother and Northamptonshire).
- Providing benefits advice through an income maximisation officer based in hospitals (Halton and St Helens).
- Offering befriending, peer support and carers' cafés (Bolton, Northamptonshire, Swindon).
- Introducing assessment and support workers to carry out Carer's Assessments on behalf of the local authority (West Kent)

All sites focused on making support accessible to carers. Breaks sites explored new approaches such as on-line booking systems and ways of providing a break without requiring carers to complete a Carer's Assessment. Health Checks sites offered the checks in a variety of venues including carers' own homes and local community centres. The NHS Support sites offered new ways of delivering Carer's Assessments and helped carers access a wide variety of other support.

Sites found demand for services was difficult to predict and needed to be extremely flexible in adjusting the services offered to meet carers' needs in a timely and appropriate manner.

Partnerships and multi-agency approaches

The vision for future support of carers set out in the 2008 National Carers' Strategy implied significant change in the health and social care system, and the DS programme aimed to explore the wider implications for the people and organisations involved. In developing the new services, staff roles in the sites often changed, multi-agency partnerships were developed and new working relationships emerged.

The impacts of the new partnerships on staff were wide-ranging, and included: improved teamwork; greater carer awareness; new activities (to engage with carers not previously in touch with support services); and developing new skills. Some staff reported an increase in their workloads, with the voluntary sector organisations involved in outreach activities particularly affected.

[1] The approach used in the Camden site built on similar previous work with a local carers' organisation.

Staff experiences varied according to the different approaches to carer support taken by the sites. Some staff needed to work in carers' homes, others had to work imaginatively to overcome some colleagues' reluctance to engage with the new services. Health and social care professionals nevertheless reported relatively few problems in integrating DS activities into their existing roles; this included staff in NHS roles in both primary care and hospital services. Some staff needed specific training to assist them to adjust to the new working arrangements, particularly in the NHS Support sites; a successful example of this is provided below.

Carer awareness training for staff in an NHS Support site

The NHS Support site in Bolton (led by a mental health NHS foundation trust) conducted staff surveys prior to delivering the DS activity. Results showed that many clinical staff (e.g. nurses in hospitals) lacked knowledge of how to support carers. Responding to this, the Bolton site developed a training course which it delivered as part of the trust's mandatory induction for all new staff. This focused on respecting carers as expert partners, carrying out effective Carer's Assessments, and providing support to meet carers' service needs. This training was effective in providing staff with a greater knowledge and awareness of carers, and with skills and knowledge about their support needs which could be incorporated into their everyday working practices. Surveys conducted after the training showed that 84% of staff said that the course had been appropriate to their role, and 88% said that it had 'broadened / refreshed their knowledge of the caring role.' This training course was supplemented by an e-learning package which could be accessed at any time by staff working in the organisation.

Source: Bolton Local Evaluation report.

Most sites developed partnerships which included voluntary sector groups, NHS organisations, and local authorities. Most Breaks sites were local authority-led; NHS Support sites were NHS-led; leadership arrangements in the Health Checks sites varied. Most partnerships were formally established with clarity about roles and responsibilities and governance which included carer input. Some found it beneficial to develop informal networks, particularly to support outreach to specific target carer groups.

The benefits of partnership working included improved carer support procedures, monitoring systems, communication networks (across the health and social care system), and more effective and comprehensive carer awareness training for staff.

Some difficulties were encountered in some sites by the partner agencies and organisations. These included: collaborating in the context of different organisational procedures and / or access to resources; a disappointing level of commitment among some partners; some concerns in local voluntary organisations that carers registered with them might be drawn away, possibly undermining their future capacity to attract funding; and differential engagement among GPs. The sites with most success in engaging with GPs adopted specific strategies to develop the role of GP practices in delivering support to carers.

Engaging GPs in innovative ways

Staff in Derby, a local authority-led site delivering a wide range of Breaks services (including alternative care in the home and well-being support / services, anticipated difficulties in engaging with GPs and took several steps to facilitate effective co-operation, including:

Recruiting a PCT development worker to negotiate with GP practices. This proved very effective and staff in this site wished they had done this earlier.

Appointing 20 'carer champions', with existing staff in 32 local GP practices allocated this role. The champions provided information and drop-in advice sessions for carers attending appointments, either when visiting a GP alone or when attending with the person they cared for.

Arranging regular network meetings, including staff from all organisations involved in delivering the DS programme, through which carer awareness could improve and knowledge and experiences could be shared.

Running awareness-raising sessions for GPs and health workers, including developing an on-line toolkit they could use.

Creating an electronic referral system for GPs to use when referring carers to the Breaks service. This was implemented successfully and included a 'feedback mechanism' informing the relevant GP of the outcome of any referral.

Source: site documents from the Derby Breaks site.

The changes in staff roles, multi-agency partnerships and working relationships had a positive effect on system responsiveness and care co-ordination, with a beneficial impact on the quality and accessibility of carers' services. An example of how the DS partnerships led to improvements in care co-ordination and system responsiveness is presented below.

Improving care co-ordination and system responsiveness

In an NHS Support site (Halton and St Helens), care co-ordination and system responsiveness were improved by a partnership through which voluntary sector staff (from a carers' centre) were based in a hospital (and assigned NHS email addresses). These staff approached carers attending hospital appointments who were not in touch with other services, providing them with support and advice and signposting them to the health checks programme. Staff in the carers' centre and the hospital felt they had benefited from this new opportunity to work together.

Source: case study interviews.

Identifying, engaging and involving carers

Establishing new and innovative ways to identify carers, engage them in the services offered and actively involve them in designing, delivering and evaluating carer support were important objectives of the DS programme.

The 25 Demonstrator Sites supported a total of 18,653 carers (5,655 in Carers' Breaks sites; 5,441 in Health Checks sites; and 7,557 in NHS Support sites). A further 28,899 carers were contacted[2] by the sites but did not receive services. The target numbers of carers that sites planned to engage with varied, as did the extent to which targets were achieved. In general, NHS Support sites were more successful in engaging with their target numbers of carers. Five sites met or exceeded their overall carer targets (Hertfordshire, Breaks; Redbridge, Health Checks; Hastings and Rother, Swindon, and West Kent, NHS Support). Five more almost reached their targets (Bristol and Suffolk, Breaks; Devon, Health Checks; and Halton and St Helens and South West Essex, NHS support).

Most sites identified several different target groups of carers to engage, including ethnic minority carers, carers of people with dementia, Gypsy and Traveller carers and carers of people with substance misuse problems.

The profile of carers supported by the sites was one of predominantly older, female carers. Sites had considerable success in engaging with carers from ethnic minority communities, particularly the Breaks and Health Checks sites. Carers of people experiencing dementia, mental ill-health, long-term / terminal illness, learning disabilities and substance misuse were also well represented in the sites, when compared to the national profile of carers.

Success in engaging with carers generally and with target groups specifically was determined, in part, by the types of engagement initiatives that sites selected. Although some sites faced initial challenges in engaging GPs and other healthcare professionals, partnerships involving NHS organisations were important ways of identifying and engaging with carers, particularly in NHS Support sites and also in some Health Checks sites. The two NHS Support sites which supported the highest number of carers (Halton and St Helens and Hastings and Rother) both identified and engaged with carers in hospitals and GP practices.

Sites which were more successful in identifying and engaging with large numbers of carers, and in meeting their planned targets, often used a combination of different techniques and strategies: adopting specific, tailored initiatives for targeting certain groups of carers (such as those from ethnic minority communities); and ensuring

[2] Many sites used mass marketing techniques, contacting large numbers of carers in this way. Those contacted did not necessarily take up services.

that, where appropriate, these efforts were on-going rather than one-off initiatives. There was a widespread view among staff in many sites that it was important to avoid the term 'carer' in marketing materials and when talking to carers, particularly when attempting to engage those previously unknown to service providers.

Example of good practice: working with healthcare professionals to identify carers

The Halton and St Helens and Hastings and Rother NHS Support sites engaged with large numbers of carers by working with healthcare professionals to identify them. Both these sites deployed specific techniques to encourage healthcare professionals to engage with the DS programme, after initial attempts were unsuccessful. Successful techniques used by these sites included:

- Ongoing awareness training on what a carer is and how to identify carers.
- Project support / liaison workers 'visible' in wards, hospitals, and GP practices to remind staff about referring carers.
- Giving feedback to GPs and hospital staff on outcomes for carers to demonstrate the benefits of the services, and to help build relationships of trust.
- Using techniques which saved health professionals' time: note pads for referrals on GPs' desks; flexible training to fit with health professionals' schedules; concise information materials.
- Regular newsletters to keep GPs updated.

Source: case study interviews.

Partnership working with organisations outside the health and social care system (e.g. educational institutions) and with voluntary sector organisations (including carers' centres) also played an important role in the sites' capacity to engage with carers. Breaks sites were most likely to use these methods of engaging with carers. Innovative approaches to reach young carers through partnerships with educational and youth organisations such as schools, colleges, youth centres and universities worked particularly well, as did outreach work through voluntary sector organisations to engage with ethnic minority carers. Gaining the trust of carers through these kinds of face-to-face methods was seen by staff as a more effective way of engaging with carers than some of the other marketing strategies used in some sites, such as websites, advertisements, posters and leaflets. Sites which spent more on marketing were not necessarily more successful at engaging with large numbers of carers. The Devon Health Checks site was successful in engaging with a large number of carers and used a combination of marketing techniques.

Example of good practice in engaging carers

The Devon Health Checks site successfully met and exceeded targets for carer numbers, and delivered the highest number of health checks. A combination of various marketing techniques was used to identify carers, including: events, working with clinical staff and using existing registers, promotions in the local media, leaflets, website promotions, publicity in GP practices and specific clinics.

To overcome initial challenges in obtaining target numbers of referrals from healthcare providers including GPs and pharmacies, additional methods were deployed including: more targeted public promotion (e.g. radio, local newspapers) in areas where provider delivery was low; offering extra support to providers which were struggling to deliver; utilising additional providers; and regularly sharing with providers suggestions for good practice in identifying carers. Efforts were made to avoid using the term 'carer' in later publicity materials.

Tailored methods were used to identify ethnic minority carers through working with the Hikmat BME Centre, which identified carers by drawing on detailed local knowledge of service users, running awareness sessions at the Centre and at the local mosque, and connecting with other local ethnic minority groups.

Sources: final report, quarterly calls, site documents.

All sites attempted to involve carers in designing services, and nine sites involved carers directly in delivery, three of which (Halton and St Helens, South West Essex, Suffolk) also succeeded in engaging with large numbers of carers and / or meeting their original targets, indicating that the nature and level of carer involvement may have been one of the factors contributing to their success.

Sites also attempted to involve carers in the evaluation of their services. Again the level and nature of this involvement varied. Some sites engaged carers in all stages of the process including service design, delivery and evaluation, with the Torbay site a good example of this.

Example of good practice: involving carers in design, delivery and evaluation

The Torbay Breaks site involved carers throughout the design, delivery and evaluation stages of its work, both as paid employees and as volunteers.

In programme planning, carers were represented in various task groups, on the project board, and at operational management team meetings.

Carers were involved in delivery through: the design, development and moderation of a local carers' website; running groups and classes at the carers' centre; marketing; delivering awareness training; and assisting with various campaigns to publicise the project and reach 'unknown' carers.

Carers also participated in the local evaluation as 'carer evaluators', contributing to the design of questionnaires and conducting peer interviews with carers. The Torbay site gathered feedback from carers involved in the project, and from carers interviewed by carer evaluators.

Sources: case study interviews; quarterly calls; site documentation.

Involving carers in the design, delivery and evaluation of sites was seen by staff as one of the elements that worked particularly well in the DS programme; it offered an alternative perspective to that of social and healthcare professionals, sometimes raising issues professionals had not considered, and benefitted the carers who were involved in a number of ways. Some sites planned to continue developing carer involvement in service delivery, which staff described as a significant 'legacy' of the DS programme.

Impact on carers

The Demonstrator Sites programme aimed to make a contribution to the evidence base on good practice in delivering carers' services. In all three types of site, services were delivered to carers with diverse characteristics and in a wide range of circumstances, with staff in the sites committed to meeting carers' needs in a 'personalised' way.

Information was collected, through Individual Carer Records, on 5,050 (27%) of the 18,653 carers who received DS services. These data showed that carers accessing the DS services and support were considerably more likely than carers in general to be older, female, to have been caring for ten years or longer and to be caring for 50 or more hours per week. Carers in ethnic minority groups were well represented, as were carers of people with particular conditions such as: dementia; mental ill-health; long-term / terminal illness; a learning disability; or substance misuse problems.

To gain an understanding of how they experienced and responded to the DS services some carers accessing DS services were surveyed through the national evaluation study and were asked about a range of issues: how they became aware of the DS service they accessed; whether they had received similar services or had relevant support before; what they thought of the services they accessed; how they felt their health, caring situation, and selected activities and behaviours had been affected by their engagement with the service.

The carers supported by the sites were strongly positive about the services and other help they received, making very few negative comments. The vast majority said they would recommend the service to other carers. Some views on the DS service are outlined on the opposite page.

Carers' views of the Demonstrator Sites services

Breaks

It has helped me feel valued as a carer. I feel carers are like an invisible army, often doing care work for family 24 hours a day, seven days a week, 365 days a year, year after year. We deserve recognition and financial help; the scheme has also boosted my self-confidence and mental and physical well-being.

The carers' breaks service is an excellent service, it gives the carer a chance to unwind and do their own thing.

Health Checks

I think this is an excellent service as it checks on the carer who often does not check their own problems.

The carer's health check I have just had at my own GP surgery was a great help. I now know the hour spent has given me help and support on my doorstep. I will now access the services pointed out to me, and they are helping me put together an emergency plan for the future. I have no siblings so I am a single carer, now with help at hand. Thank you.

NHS Support

Without this help I would have felt very alone and would not have understood how to cope.

As I have been a carer for many, many years, my answers may not appear to be particularly positive. However, as a result of services received, my aims / attitudes have been reinforced and I have been able to use my knowledge etc. to help and support other (newer) carers.

Source: Demonstrator Sites carers' survey, University of Leeds.

In the Breaks sites, 80% of carers responding to the survey were people who had not previously been able to take a break from caring for more than a few hours a week, and in the NHS Support sites, particularly those identifying carers in hospitals, many carers had never before received support to help them in their caring role. Most respondents who accessed the Health Checks sites had seen a healthcare professional about their own health in the past six months; their appreciation of the new emphasis on well-being, and the more holistic approach taken (with time to feel listened to and supported) often came through strongly.

Accessing the DS breaks services enabled some carers to have more of a 'life of their own' and build confidence; some also reported changes in their behaviour which were beneficial for well-being or health. A third started a new leisure activity, and some reported improvements in their communications with professionals and knowledge of carers' entitlements. Carers who did not receive a break were more likely to show deterioration in well-being scores.

The health checks offered had a positive impact on a large minority of those supported, although 45% of carers felt that 'safety in being a carer' (e.g. lifting and handling) was not covered in their check. Four months after the health check a quarter of carers said that both how they looked after their health and the amount of exercise they took had improved and most carers had been signposted to additional services. A few carers said this had not been helpful, suggesting care needs to be taken in referring carers to other support that it is both appropriate and followed up. For some carers the benefits of the DS support were wider than they or the sites had anticipated, and led to unexpected positive consequences (as shown below).

Unexpected positive outcomes for carers

Learning all the skills to cope has helped me with confidence and my outlook on the situation. I have now started up a new successful business because of all that has happened

I have a better relationship with my own children and their families.

Source: Demonstrator Sites carers' survey, University of Leeds.

Costs and benefits

It is widely recognised that carers save the economy a significant amount of money, both in terms of the direct value of the support they provide and because the care they provide either avoids, or delays, the need for long-term services, hospitalisation or residential support (Wanless, 2006). The economic value of the contribution carers make in the UK has been calculated to be £119 billion per year (equivalent to £18,473 for every carer in the UK), a figure which rose by 37% between 2007 and 2011 (Buckner and Yeandle, 2007; 2011).

The cost savings associated with carers are often put forward in support of the business case for providing support to them. However, it is not always easy to make a direct link between investment in support for carers and cost savings or costs avoided. Through the DS programme, the DH was seeking to gain a better understanding of which models of delivery and which kinds of carer support are cost effective, both in terms of their direct provision and in terms of the wider potential cost savings in the health and social care system.

The DH invested over £15 million in the DS programme for the duration of 18 months, which was supplemented by more than £4 million of additional funding from other sources. The 12 Breaks sites were allocated just over £8 million of DH funding, the six Health Checks sites were awarded just under £3 million, and the seven NHS Support sites over £4.5 million.

Total overall site costs and cost per carer supported varied substantially both within and between the three different types of site.

Costs of service delivery and cost per carer supported[1] in each of the Demonstrator Sites

Breaks: Total spending £283,563 - £2,253,026; total cost per carer supported £603 - £6,000.

Health Checks: Total spending £229,855 - £982,839; total cost per carer supported £336 - £2,336.

NHS Support: Total spending £570,499 - £783,857; total cost per carer supported £171 - £1,483.

Source: QRTs, University of Leeds.
[1] Calculated by dividing total expenditure (DS funding plus any local resources added) by the number of carers supported.

All three types of carer support have the potential to deliver cost savings both to the providing organisation and to the health and social care sector. Potential cost savings identified through the national evaluation study and in the local evaluation reports include:

- *Preventing hospital or residential care admissions:* By supporting carers and preventing deterioration in their health, the need for emergency admission to residential care of the person being cared for when their carer falls ill can be avoided. This saves on the costs of accident and emergency attendances and inpatient stays. There was anecdotal evidence from staff interviews and carer case studies in all types of site indicating that the DS services had the potential to prevent carer breakdown and reduce hospital admissions among carers and those they care for.
- *Supporting carers to sustain their caring role:* Supporting carers effectively can enable them to continue caring longer, reducing the need for more costly residential care or community services for those they care for. Qualitative evidence (in all types of site, especially Breaks sites) showed the DS activities had enabled some carers to sustain their caring role for longer.
- *Earlier identification of physical and / or mental health issues:* One the key hypotheses of the DS programme was that undertaking health and well-being checks and identifying undiagnosed conditions could provide significant cost savings if, and where, long-term conditions and more expensive medical interventions were avoided. Both quantitative and qualitative data gathered in the local and national evaluation studies showed that health checks frequently led to diagnosis of previously unknown conditions, with high levels of referrals for further medical intervention.
- *Improved health and well-being of carers:* Maintaining the health of carers through appropriate and early well-being support, combined with regular targeted health checks, can delay the onset of health problems and enable carers to maintain their caring role. All types of site reported examples (in local evaluation reports) of improvements in carers' health and well-being following the DS intervention, sometimes supported by improvements in carers' health and well-being scores.

- *Improved partnership working:* This led to better care co-ordination, offering scope for cost savings through: pooling resource inputs from different organisations; avoiding duplication of services; higher take-up of services through improved carer awareness; new pathways to prevent re-admissions and patient / carer breakdown; and signposting of carers to other support or services enabling them to continue caring for longer. Data from staff interviews and local evaluation reports indicated that the programme led to improved partnership working between NHS, local authority and voluntary organisations, leading to better working relationships, signposting and referral processes.
- *Efficiency savings in GP practices:* Cost savings can be achieved by: reducing DNAs (failure to attend scheduled appointments); helping carers to attend GP or hospital appointments and maintain their own health and well-being; reducing carer GP visits; identifying and treating health issues earlier, potentially avoiding more costly later medical intervention; and enabling carers to continue caring for longer, preventing admission of the person cared for to residential care. Evidence from interviews with staff and local evaluation reports in several sites indicated that the DS activity had led to efficiency savings within GP practices.
- *Assisting carers to return to, or remain in, paid work:* The cost savings of assisting carers to remain in, or return to, paid work are potentially very large. Carers miss out on an estimated £750m to £1.5bn in earnings, a vital potential contribution to the economy (Buckner and Yeandle, 2011), and a lack of suitable services for the person cared for is a key barrier to carers remaining in paid work (Yeandle et al, 2007). Although evidence for this in the DS programme was limited, staff interviews and some local evaluation reports indicated that the support provided (e.g. replacement care, support in accessing training or jobs) enabled some carers to return to / remain in paid work.
- *Informal networks of support among carers:* Developing informal support networks of carers can reduce the need for alternative services and their associated costs. Several local evaluation reports showed that some DS services helped carers meet with other carers and build local support networks. Some sites also facilitated the involvement of friends and relatives in providing replacement care, enabling the carer to have a break without incurring replacement care costs.

Providing robust evidence in the form of quantifiable costs savings presented a considerable challenge for the national evaluation team and the local site evaluators. Three Breaks sites (Derby, East Sussex and Sunderland) and one NHS Support site (Halton and St Helens) made progress in calculating the cost savings of their service, using different approaches. In all four sites positive cost savings were reported.

Many sites continued to offer all or part of the carers' support services developed within the DS programme despite their DS funding coming to an end. Four sites: East Sussex and Hertfordshire (Breaks); Devon (Health Checks); and Halton and St Helens (NHS Support) clearly demonstrated, with evidence, that the carers' services they developed have the potential for sustainability in terms of all the following measures: the type(s) of approach adopted; the total spent; the number of carers supported; and the outputs and outcomes of the support offered. All four of these sites continued the DS service (or elements of it) beyond 31st March 2011 (when the DS funding ended).

Conclusions and policy recommendations

Publication of this report in autumn 2011 coincides with the government's engagement exercise on the 'Future of Care and Support', providing an important opportunity for learning from the DS programme to be applied as new arrangements are put in place after 2012, when the Secretary of State for Health plans to publish a new White Paper on Care and Support.

Impact on carers: evidence-based conclusions

- The DS adopted approaches which worked well in targeting some of the neediest carers. Future services need to take care to ensure that the needs of male carers and of younger carers are not neglected.
- Most carers supported by the DS felt they benefitted from the kinds of services offered, finding them a suitable way of meeting some of their otherwise unmet needs.
- Support of the type offered in the Breaks and NHS Support sites filled an important gap in services for carers, and services of this kind should be prioritised. The well-being support offered in Health Checks sites was a new form of support for most who received it, filling a previously unmet need, and should also be developed.

- Flexible and personalised breaks support is life-enhancing for many carers. It has the potential to prevent carer burn-out / health deterioration and to help sustain their caring role.
- Health and well-being checks led to sustained self-care and healthier behaviour for some carers. Arrangements for signposting carers to support need to be carefully monitored for their suitability and effectiveness in each individual case.

Innovation and effective practice: evidence-based conclusions

- Staff in the NHS, local authorities and voluntary sector organisations, working together, developed a wide range of creative and sometimes innovative approaches which worked flexibly for carers and offered them personalised support.
- Standardisation and uniformity is not appropriate in developing and delivering carers' services, but flexibility and responsiveness to local circumstances can work well. The allocation of leading and supporting roles within partnerships should reflect local priorities, needs and circumstances.
- Some carers derive significant benefit from relatively low-cost support at appropriate points.
- Well-being support was offered in a variety of settings, in different ways: some options valued by carers do not rely exclusively on input from fully qualified clinical staff.
- Some success was achieved through establishing 'carers' champion' roles in GP practices, linked to other partner agencies and support. 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.
- Carers access support via different routes, according to their own caring circumstances. Services need to be accessible at key points in the carer's journey, especially when caring first arises, at points of change or stress in their caring situation and on a regular basis when caring is long-term and intensive.

Partnerships and multi-agency approaches: evidence-based conclusions

- Multi-agency support for carers can be developed without an unduly disruptive effect on the workloads of staff in the health and social care system. Organisations should expect initial setting-up of new arrangements to be time-consuming, however, and a flexible approach to job content and professional roles may sometimes be required of some staff.
- In developing carer support, voluntary sector organisations play a key role and may provide expertise not available elsewhere. In planning service implementation, care should be taken to avoid over-burdening voluntary sector staff and to ensure that their roles and activities are adequately resourced.
- Some of the carer support offered in the DS required additional training for staff in some or all partner organisations. Carer awareness training is likely to be particularly necessary in NHS organisations, and voluntary sector organisation staff may need additional training for specialist roles, such as delivering well-being checks to carers.
- Organisations in all segments of the health and social care system should be encouraged to take on leading roles, where appropriate, to deliver carer support. It should not be assumed that local authorities need to lead all developments, although involvement of relevant local authority services is likely to be beneficial for most carer support projects.
- Organisations bring different practices and systems to partnerships, and how to integrate these requires careful consideration when new developments are planned. Special approaches may be needed to encourage GPs to engage with carer support arrangements. The previous work of local carers' organisations in building local intelligence on carers and their support needs should be valued and discussed when projects are designed.
- The DS programme leaves a legacy of documentation and tested processes on which future development of support for carers can build.

Identifying, engaging and involving carers: evidence-based conclusions

- Careful consideration of local needs and circumstances can help multi-agency partnerships to target carer support towards those in greatest need. The DS programme provides many examples of effective ways of targeting specific groups of carers.
- There is considerable scope for extending and improving carer support through NHS-led initiatives developed in partnership with relevant agencies.
- Targeting carers in line with local priorities works well, but as other evidence indicated, male and younger carers may be missed if not specifically identified.
- Effective support for carers requires strong multi-agency partnerships supported by additional networks, within and beyond the health and social care system, to support carer identification, engagement and involvement.
- In recruiting carers, agencies rely heavily on word-of-mouth and face-to-face contact and many lack the capacity and expertise to mount really effective local marketing campaigns.
- Good practice in involving carers means including them in project planning from the start, ensuring they have adequate support and training in the roles they play, drawing a diverse range of carers into projects, and being attentive to, and flexible about, challenges in involving them. Carers may face difficulties in participating regularly in relevant meetings and processes, and this needs to be recognised and accommodated.

Costs and benefits in the health and social care system: evidence-based conclusions

- Variable prior experience, different targets and complex configurations of support made identifying which DS sites offered best value for money impossible. As some of the service and support options developed are rolled out more widely, opportunities will arise to compare similar projects and identify efficiencies in delivering them.
- The wide range of ways in which cost savings may potentially be made, given the relatively modest costs of providing carer support, suggest that continuing to expand support for carers, especially when caring begins, for those with intensive or long-term caring roles, and when carers experience strain, is likely to be a financially sustainable approach. While some sites made some progress in calculating costs savings, it may never be possible to put an accurate figure on the precise costs saved. The DS programme showed positive health and well-being outcomes for substantial numbers of carers and very positive carer responses to relatively low-cost support.
- Further work on building suitable tools is needed if the cost-effectiveness of carer support is to be measurable. The DS programme, or similar programmes in which different sites are tasked with innovation and experimentation, are not ideal vehicles for measuring costs and benefits. More controlled interventions, over longer time spans, ideally with comparator groups, would provide a more suitable environment for this type of measurement.
- Organisations bring different practices and systems to partnerships, and how to integrate these requires careful consideration when new developments are planned. Special approaches may be needed to encourage GPs to engage with carer support arrangements. The previous work of local carers' organisations in building local intelligence on carers and their support needs should be valued and discussed when projects are designed.

Policy recommendations

- **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.** Partnerships, which might operate as, through or in consultation with health and well-being boards, and may build upon or further develop existing local partnership arrangements, should agree future-oriented local strategies and budgets for carer support which enable them to plan, develop and implement suitable services. This approach is consistent with guidance already issued to PCTs by government in 2010.

- **Local carer support partnerships should involve a diverse range of carers in service development**, offering them suitable training, and should work with them to review carers' needs, identify local priorities for developing carer support, and select the leading and supporting agencies needed to deliver different types of carers' services.
- 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.** To establish and sustain support for some groups of carers, flexible networks, where appropriate involving agencies outside the health and social care system which are trusted by carers or which work with people who are carers, may be required.
- No single type of carer support is best or offers a panacea for all carers or all caring situations. **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. Flexible and personalised services need not be expensive, but must be available to carers in a timely manner and capable of responding rapidly to carers' needs, which can arise unpredictably or unexpectedly.
- **Portfolios of carer support need to be agreed locally** between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate. Carers need support with: health problems and stress; information on how to access suitable support, services, equipment and home adaptations for those they care for; income maintenance and pensions protection during and after caring; self-care, healthy lifestyles and maintaining a life outside of caring; access to education, training, work and leisure; emergency planning; and how to access occasional or regular breaks from their caring role.
- **Hospitals should routinely provide mechanisms to identify and support new carers**, centring 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. Timely and co-ordinated support for new carers and carers with changing care responsibilities, linked to follow-up services, should be available in every acute hospital and advertised in all out-patient clinics.
- All GP practices have contact with carers, even if this is not always recognised locally. **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. These workers may require carer awareness and carer support training. The action guide 'Supporting Carers', for GPs and their teams, published by the PRTC and the RCGP in October 2011 provides detailed suggestions for practical ways of taking this forward (PRTC and RCGP, 2011).
- **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 be equipped to advise on how a carer can access a health and / or well-being check. Checklists, protocols and guidance for professionals and support workers which have been developed and tested in the DS programme should be made widely available in the health and social care system, and all relevant workers should be trained to look for signs of stress or of deteriorating health among carers and to offer guidance on suitable support. Local partnerships should consider resourcing local voluntary sector organisations to deliver well-being checks for carers.
- Many workers in the health and social care system, particularly (but not only) in the NHS, could provide more effective support to carers if they had benefitted from carer awareness training. **All relevant organisations should regularly offer carer awareness training to their staff.** Training need not be costly and for some staff groups, on-line or web-based training modules may be an inexpensive and appropriate option.

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About the report

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About the study

The evaluation study on which the report is based was carried out in 2009-11, commissioned by the Department of Health. Contributors to the chapters in the full report are: Lisa Buckner, Christina Buse, Gary Fry, Viktoria Joynes, Ben Singleton, Andrea Wigfield and Sue Yeandle.

About CIRCLE

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