NEW DEAL FOR CARERS:
Revision of the Prime Minister’s
1999 Strategy on Carers

Health and Social Care Taskforce
Report

This is a report to government. The Task Force membership comprised representation from central and local government, professional bodies and third sector organisations. A full list of members can be found attached at Annex B.
NEW DEAL FOR CARERS: Health and Social Care Task Force Report

Introduction:

The Health & Social Care (H&SC) Task Force, the membership of which is set out in annex B, was one of four such task forces established to develop proposals for measures to be included in the new Carers’ Strategy. This report comprises proposals developed by the group which were put to the Interdepartmental Group chaired by David Behan, Director-General Social Care, Local Government and Care Partnerships, Department of Health, which oversaw the development of the strategy as a whole.

The H&SC Task Force held its first meeting in July 2007. The task it was set was to discuss and develop prioritised proposals for new or enhanced interventions in the field of health and social care which would improve the support provided to carers and help them achieve a life outside caring – a key outcome identified at an early stage in the task force’s deliberations.

Each member of the task force was invited to put forward proposals to be considered by the group as a whole. A process for voting from a long list of about 56 proposals resulted in the prioritised list set out in this report – a list put forward with the full consensus of the group.

During the meetings, it was made clear that there was limited prospect of large additional resources being made available in the short term (i.e. for the remainder of the comprehensive spending review ending in March 2011.) However, since the carers strategy was to last for 10 years the group was encouraged to think in terms of what might be considered which could be implemented in the short-term with limited resources as well as developing proposals for consideration for implementation in the longer-term.

The group included an assessment of likely costs of the proposals they were making although each proposals finally short-listed was subject to a more rigorous resource cost/benefit analysis. The taskforce members who made the proposals and the analyst and policy teams from the Department of Health and Department of Children, Schools and Families worked up the proposals and provided specific policies that which might be implemented to try to meet the intended outcomes signalled in the proposals.

At the final meeting of the task force, on 13/2/08, members were asked to prioritise a small number of items from the proposals that would go forward to Ministers as key issues they need to address. The four key areas to address are:
  i)  Information
  ii)  Breaks
  iii) Services
  iv) Young Carers

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1 Carers at the heart of 21st-century families and communities, HM Government, 2008
The major themes identified by the taskforce as underpinning their work are:
- Support for carers to lead a life outside caring
- Information
- Advocacy
- Access to services
- Recognition
- Diversity
- Young Carer issues

The proposals finally submitted are listed in annex A.

For further detail on the proposals please see the Health and Social Care Impact Assessment.

Public consultation:

A public consultation, run by Opinion Leader, which started in June 2007 ran in parallel to the Task Force process identified above.

The findings from the consultation, set out in the papers prepared by Opinion Leader, generally supported the proposals put forward in the taskforce. The taskforce examined their proposals in light of the consultation and looked at whether the proposals covered the major issues raised in the consultation.

The key areas for action, relating to the Health and Social Care Taskforce, that were prioritised by carers across the country were information, break provision, cohesion between services, recognition of a carer’s role, the physical and emotional impact of caring and attitude of others. On young carers, the priority was better support around the family and the person cared for, followed by greater awareness and understanding from frontline settings such as GPs and schools and more targeted and project-based support for young carers themselves.

The taskforce felt that the proposals they had prioritised, and work in the strategy as a whole, covered the majority of areas raised by carers as needing action in the consultation.
Annex A

Proposal 1: To provide improved and more consistent information and support targeted at all groups of carers and transitions

Context

- The information helpline and website will go a long way to ensuring that carers are able to access reliable and consistent information when they need to;
- In addition, Information Prescriptions will be available to all patients with long-term care needs and their carers from the end of the year;
- Information is a major part of Putting People First\(^2\), which signals the commitment across central and local government, the NHS and other sector leaders to work together to support individuals and their carers.

However, gaps were identified in the provision of information specific to one’s locality and one’s need. Therefore, the following recommendation has been made.

Recommendation

Funding to provide information/signposting specific to the individual and locality (i.e. what is available to a carer in their area, as distinct to the concept of universal information via lots of outlets which cannot point you to your nearest parents of ADHD children coffee morning, etc.).

This was identified as a relatively low cost measure which could be implemented in the short to medium-term.

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\(^2\) Putting People First, HM Government, 2007
Proposal 2: To increase the availability of care breaks

Context

- The inclusion of the following words in the Operating Framework for the NHS should open a route for NHS funds to be spent on providing care breaks;

  “PCTs should aim to create a more personalised service that provides […] support for carers by (among other things) taking on board their views about the people they care for, and recognising their need for breaks from caring.”

- In addition, the inclusion of breaks in the guidance for Practice Based Commissioning should also see more NHS money spent on breaks in the future;

  “Purchase of respite care – to allow carers to take a break, particularly families of children with a disability, or when patients with a terminal illness need more intensive nursing for a fixed period of time.”

- In addition, individual budgets (IBs) and direct payments offer carers and the person cared for the opportunity to buy breaks using the money paid too them from local authorities. The evaluation of the IB pilots includes a specific evaluation of how IBs have benefited carers.

These policy developments should result in an increase in the provision of planned breaks beginning in the short-term and building over the life of the strategy.

Recommendations

1. Pilots to evaluate the current provision of breaks for carers and to look at innovative approaches to providing breaks and the most cost-effective way to provide breaks.

2. The Task Force decided that the best approach to take with Ministers in trying to increase the money put into the system is to provide a menu of options of how many breaks certain amounts of money would buy. Examples of some of these costings are detailed in the table below:

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4 Practice Based Commissioning – budget setting refinement and clarification of health funding flexibilities, incentive schemes and government, Department of Health 2007
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<th></th>
<th>£100m</th>
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Proposal 3: To provide better services and support for carers

Context

- The Social Care Reform grant that supports *Putting People First* provides funding for local authorities to redesign and reshape their systems around the individual – both users and carers;
- Work is ongoing in the department to ensure that carers become part of the NHS language – through the Operating Framework, World Class Commissioning and Practice Based Commissioning.

These policy developments will result in service improvement taking place in the short-term and developing during the lifetime of the strategy.

Recommendations

1. **To provide a specialist carer’s service** in every area where one does not already exist. The exact nature of service delivery would be decided locally, the minimum outcomes of establishing specific support for carers in every area would be:
   - early identification of carers;
   - advocacy, empowerment, involvement;
   - ongoing emotional support (as distinct to counseling which is very specific, expensive and only applicable to some carers).

2. **To improve NHS support for carers** through:
   - Evaluating existing services where there is health involvement for recognition and support for carers;
   - Establishing pilot sites to develop services in primary and acute care which recognise and support carers and their contribution throughout pathways;
   - Funding an evaluation of these pilot sites to establish a business case for these services nationally and also to develop tool kits and best practice guides.

3. **To provide better training for GPs in working with carers.**
   - To develop, pilot, evaluate and, subject to a positive evaluation, roll-out nationally a training programme for GPs, in conjunction with RCGP, to help them support and interact with carers in a more productive way.
Proposal 4: To provide better support and services for young carers and their families, ensuring that children are better protected from falling into inappropriate caring

Context

- £3m provided over the three years to 2011 to model & test within six local authority (LA) areas new preventative forms of support around families at risk of relying on the care of a child. This funding will also cover, over the same period, evaluation and dissemination of learning to other LAs across the country.
- £600,000 provided over the three years to 2010 to the Children’s Society & PRTC to develop new guidance on whole family working/good practice principles. Over next two years, training based on the guidance will be provided for one LA in every region. Three national roadshows are also planned to enable other LAs to access the training.
- £370m provided over 2008-2011 to increase support and short breaks to families with disabled children. This significant strengthening of support around families with disabled children is likely to bring benefits for the whole family including any youngsters in those families who assist with caring. The 2004 Dearden & Becker survey of young carers suggest that some 30% are undertaking caring because of a disabled or sick sibling in the family.
- Parenting support. Range of new investments now underway to strengthen parenting support generally. Particularly relevant is the Parenting Implementation Project (PIP) whose work in 08/09 will include new ways of reaching supporting vulnerable/hard to reach parents, including parents with disabilities whose children may be young carers.
- Schools-based work. Number of national programmes now rolling out across schools which are designed to strengthen the wider support available to all pupils, ensure better home/family links, build emotional resilience and foster more inclusive and supportive environments for all pupils. These include the National Healthy Schools Programme; Social and Emotional Aspects of Learning (SEAL); parenting support; extended service schools; and new investments in support for emotional well-being and mental health linked to schools.

Specific Recommendations

1. Extending action to promote across all LAs preventative “whole family” approaches to assessments and service delivery so that children are protected from falling into inappropriate caring. Mental health and substance misuse teams to be particularly targeted.

2. Research to be conducted to inform the need for funding/further service development over the longer term.
3. Shared indicator between adult & children’s services to be considered as part of the next (2011) CSR. Indicator to measure the extent to which young people are protected from excessive or inappropriate caring roles.

4. A tailored programme of training and awareness-raising among GPs and PCTs and hospital discharge teams.

5. Within schools and colleges, young carers better embedded within pastoral support and relevant mainstream programmes including Healthy Schools/healthy colleges, extended schools, Personal, Social and Health Education and Social and Emotional Aspects of Learning.

6. Awareness raising across all schools/colleges to de-stigmatise illness/disability and promote positive understanding of caring-

7. Strengthening/expanding targeted/project-based provision for young carers

8. Capturing and sharing information on best practice and forms of targeted support which deliver the greatest benefits so that provision continues to grow in quality and impact.

9. Ensuring best practice becomes integral to extended schools, targeted youth support and planned expansion of emotional well-being support within schools, and Child and Adolescent Mental Health Services (CAMHS) more generally.

10. Ensuring best practice is also used to support LAs in developing/commissioning an effective, evidence-based range of young carer support services.

11. Inspection of provision of young carers services (via Joint Area Reviews & OfSTED).
Proposal 5: Legislation to place a duty of care on local authorities and health organisations to provide information to carers

It is difficult to cost this proposal without knowing what the nature of the legislation would be. Evidence from Scotland suggests that the costs associated with the proposal are likely to be focused on the provision of:

- staff training
- carer training
- carers information

Depending on whether some of the other proposals are taken forward, in particular 1, 2, and 3 the additional implementation costs of this proposal may be reduced.

In addition, it is difficult to know whether this legislation will be necessary once the effects of the other proposals are realised.

This proposal needs further work to narrow down its scope. If the resulting policy is accepted then legislation would be prepared in the medium-term and implemented in the longer term.
Proposal 6: To provide Information Prescriptions for parents with disabled children

Context

By the end of the year, everyone with a long-term condition or social care need and their carers should be given an information prescription after meeting with a health or social care professionals.

Pilots have been running in 20 sites and the evaluation report will be available in March 2008. An interim report (released in January) is available at www.informationprescription.info

Recommendation

That information prescriptions be provided to parents of disabled children at specific points during their childhood focusing on key areas of transition.
Proposal 7: Flexibility around hospital appointments so carers can attend

Context

NHS Choice is currently trying to ensure that patients have as much choice as possible when it comes to booking their outpatient appointments and any procedures that need to be carried out in terms of both time of appointment and venue. From April 2008, every patient is able to choose at which hospital they would like to have their operation performed (across the country). Choose and book allows patients to choose from a range of appointments online to get the time that suits them best.

Specific Recommendations

Carers should be offered replacement care and flexibility around appointments so carers can attend health promotion planning programmes and hospital outpatient appointments.
Proposal 8: Improve quality measures and indicators and Improve the evidence based for carers in commissioning

Context

Discussions are ongoing across government about the possible inclusion of a fourth page in the census 2011, which will include a carers’ question. A decision is expected to be reached on this, at Ministerial level, before the strategy is published.

Recommendation

- Put in place an online assessment tool and mapping exercise similar to that carried by Durham University on Child and Adolescent Mental Health Services (CAMHS);
- Collect information on carers via the census and Integrated Household Survey (although the IHS will not provide any local level information and therefore no indicators or data for commissioning at this level);
- Put in place a robust national survey of carers about their experience and satisfaction. This would entail each LA carrying out a survey locally and feeding the information back to the Information Centre to disseminate.

Proposal 9: To ensure that funding for equipment such as hoists, pressure mattresses and telecare is available when needed

Context

- In 2006, the Prime Minister launched the Transforming Community Equipment and Wheelchair Services programme. Its remit was to work collaboratively with stakeholders to develop a radical new model for delivery of community equipment and wheelchair services in England, which has users and carers at its heart;
- The move towards a more personalised social care system, through Individual Budgets and Direct Payments may allow the carer/cared for person to make small, but vital, purchases when they are needed;
- The Preventative Technology Grant (PTG) provided £80 million funding over the two years 2006-07 to 2007-08 to help mainstream and embed telecare services and to support an additional 160,000 older people stay in their own homes;

Recommendation

One of the key things that carers need and want to support them in their caring roles is better support for the person they are caring for. Priority of access to equipment and technology would be one major change which may bring significant benefits to the lives of carers.
Proposal 10: To modernise and streamline assessments

Context

The Carers and Disabled Children Act 2000 gave carers the right to an assessment independent of the person they care for. The Carers (Equal Opportunities) Act 2004 placed a duty upon councils to inform carers, in certain circumstances, of their right to an assessment of their needs.

Recommendation

In spite of the legislative changes described above carers often found it difficult to access assessments and when they do find the bureaucracy difficult and unwieldy to deal with. Improvements, such as online self-assessments, were asked for which would ensure that more carers could have assessment and benefit from the services that may result from them.

Proposal 11: Ensure that third sector organisations are funded to raise the quality and reach of carer support services

Context

- The third sector is relied upon for support by a large proportion of carers. The third sector often supports carers who are not reached by social services;

- The Department of Health currently provides funding to the third sector through its Section 64 grant programme to support the health and social care goals of the department.

Recommendation

Provide support to third sector carer organisations nationally so that they can support local third sector organisations. In particular, they should provide targeted business development, support, guidance and training to enable local providers to understand what they need to do to provide flexible services in a changing environment.
Proposal 12: Social exclusion programmes to include all carers

Context

• A significant number of carers face social exclusion due to the demands placed upon their time by their caring role. Furthermore, many carers can feel that there is a stigma attached to them due to their caring circumstances.

• The Social Exclusion Task Force, which is part of the Cabinet Office, are currently undertaking a programme of work looking at families at risk which contains a focus on young carers.

• The Care Services Improvement Partnership has a social exclusion programme which is looking at the social exclusion faced by people with mental health problems.

Recommendation

The current social exclusion programmes in government should include a focus on carers.

Proposal 13: To ensure that there are good transition protocols between Adult and Children’s services which recognise the role of carers.

Context

The Aiming High for Disabled Children programme contains a focus on transition for disabled children between child and adult services.

Recommendation

That any transition protocols for disabled children moving between child and adult services recognise the role of carers.
Proposal 14: A named key worker for each carer

Context

The Early Support Programme offers training and guidance for an individual who is currently in contact with the family/carer, e.g. a physiotherapist, care worker or GP, to take on a key worker role. The role involves ensuring that there is joint planning between all services accessed by the carer and person being supported, facilitating meetings, arranging appointments and providing advice and information.

Recommendation

A carer support worker being made available to every carer with significant needs to support them in their caring role specifically aiding with service co-ordination and navigation.

Proposal 15: Training and awareness raising for key professionals to provide better support for carers

Context

Although some local authorities offer training for professionals not just in social care but across the board it is not consistent across the country. It is important that this training takes place across the country and reaches all staff who come into contact with carers.

Recommendation

Training for all staff who come into contact with carers around how they can better support them in their caring role and to have a life outside caring. The training could range from half an hour taster sessions to whole day training courses. The modules would be tailored around the needs of the staff, i.e. specific training for housing or Jobcentre Plus staff.
Annex B

HEALTH AND SOCIAL CARE TASK FORCE MEMBERS

Craig Muir – Department of Health (DH) (Co-Chair)
Jo Webber – NHS Confederation (Co-Chair)
Graeme Betts – Association of Directors of Adult Social Services (ADASS)
Raghuv Bhasin – DH
Louise Boddington - DH
Louise Bridson – Department for Children Schools and Families
Paul Cann – Help the Aged
Angela Cannon – DH
David Congdon – Mencap
Rehka Elaswarapu – The Healthcare Commission
Clive Evers – Alzheimer’s Society
Alex Fox – Princess Royal Trust for Carers
Jenny Frank – Children’s Society
Jill Harrison – Contact a Family
Paul Jenkins – Rethink
Caroline Marsh - ADASS
Anne McDonald – LGA
Julian Oliver – DH
Natalie Pinnock Hamilton – Afiya Trust
Clare Pyper – Association of Directors of Children’s Services
Imelda Redmond – Carers UK
Anne Roberts – Crossroads
Mary Roberston – Care Services Improvement Partnership
Naylni Shanmugasathan/Raphael Wittenberg – DH (sharing role)
Richard Taunt – HM Treasury
Geraldine Teggart – Commission for Social Care Inspection