Carer Review Paper 1

Carer identification, carer awareness raising and information provision: good practice examples

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'Success Factors', Anthony Pugh, Project Manager Carers Strategy, Yorkshire and the Humber

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1 Background information

National policy context

HM Government's refreshed carers' strategy 'Recognised, valued and supported: Next steps for the Carers Strategy' was published on 25th November 2010. [1] There has been limited time for analysis, but the key messages relevant to this review are in section 1 'Identification and Recognition' where 'Priority area 1' is outlined as:

> 'Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages'

The next steps listed on page 12 of that document are also relevant.

The review process will need to involve closer analysis of this Government document.

Profile of caring

Census figures record 17,009 carers in York in 2001, and 342 young carers aged 8 – 17. The population in York has risen by 9.8%, and gives rise to an estimate in carer numbers of 18,676 in 2010. In 2009/10 CYC completed assessments or reviews for 1473 carers. York Carers Centre currently has 1959 carers registered on its database.

Carers are of all ages. Most adult carers of children and adults with severe and long-term disabilities or illnesses will be identified through provision of health and social care services. Carers of people with enduring mental health problems may also be identified when the person they care for accesses treatment. This means that carers in significant need may well be identified at the point at which the person they care for accesses health or social care services. Many carers are sustained in their role through natural support from their communities and networks.

It is estimated that 37% of the caring population start caring and a similar proportion cease caring every year in the UK, which means over 6,000 new carers in York annually. Carers were surveyed by Carers UK for a report in 2006, and 65% did not identify themselves as a carer in the first year of caring. The report recommends that information strategies target carers in the first year of caring. [2]

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[1] National Carers Strategy, November 2010.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122077
[2] The Importance of Information for Carers, Carers UK 2006, p2, p9 and 12.

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Carer identification and models of prevention

A systematic review of interventions for carers in the UK outlines that limited research evidence is available about the outcomes of information services. [3] Two reports published jointly by the Association of Directors of Adult Social Services (ADASS) and the Princess Royal Trust for Carers (PRTC) in 2010 however, provide supporting evidence that early identification can reduce risk of more intensive care being needed later on and promote better outcomes for carers and the person they look after. [4] [5]

Early intervention and prevention are important in the provision of support to carers and the people they look after, but there are differing models. This includes providing 'preventative' information and advice to people with low level needs; but can also mean taking specific actions to prevent further deterioration in people with already high needs.

It may be useful to adopt the idea of two levels of need to help inform plans about carer identification:

- **Low level need: aim to promote/maintain independence and wellbeing**
  Provision of information to carers and those they care for where there are no specific needs for social or health care interventions.

- **Higher level need: aim to identify risk, halt and/or minimise deterioration**
  Provision of information, advice and signposting to identify needs, risks and interventions required to sustain the carer in their caring role

Demographic change and Area Based Working

It is estimated that 25% of all carers in the UK are aged over 60. Based on 2001 census information 13.5% of the people in York who are aged 60+ are carers. [6]

York's older population (55+) will increase by 32.7% within the next 20 years. [7] This means that there is likely to be an increase in the numbers of carers who are older, and more demand upon people of all ages to become unpaid carers of older people.

City of York Council's (CYC) Area Based Working Pilot is underway, and one of the emerging themes is to improve lives for older people locally. This may

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[3] Victor, E. (2009) *A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence.* London: The Princess Royal Trust for Carers.
[4] Supporting Carers – Early Intervention and Better Outcomes, ADASS/PRTC, May 2010
[5] Commissioning Better Outcomes for Carers and knowing if you have, ADASS/PRTC May 2010
[6] Older Carers in the UK, Lisa Buckner and Sue Yeandle, Sheffield Hallam University/Carers UK, 2005
[7] Older People Profile Version 1, City of York Council Performance and Improvement Team, June 2010

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well provide an opportunity to share and focus resources in particular wards or local areas, by working with ward partnerships. York Carers Centre has started a programme of outreach work, focusing on making links with GP practices and concentrating on local areas e.g. Haxby and Huntington, where there is likely to be a high prevalence of carers.

2 Good practice examples from other areas

Information for carers
A variety of approaches to information provision exist in other areas:

- **Hertfordshire County Council** has a 'whole area' approach developing a 'core information offer' with commitment from every agency signed up to the Hertfordshire Carers Strategy to implement the model.
- **Nottinghamshire** commissioned Carers UK to analyse information and found that carers received similar information several times. As a result a new information pack is available which can be tailored to the individual, is available via different routes, and will be delivered through a multi-agency dissemination strategy.
- **Kirklees 'Carers Gateway'** provide 'one stop shops' where Gateway Workers assist carers to access information, services and support.
- **Wakefield** has a 'whole system' approach whereby local agencies work in partnership to provide a local based information service to carers.
- **Dudley Social Services** produce 'The Dudley Carers Guide to … Factsheets'. These are a series, which aim to signpost carers to the information and services they need.
- **North Lincolnshire** produce a guide with details of support available locally that is regularly updated and in ring binder format. The intention is for this to become a personalised reference document for the carer.
- **Oldham Carers Magazine** is produced by a partnership of carers working with PCT and local authority partners to produce a 'high street' style publication.

Carer Identification
- **NE Lincolnshire Care Trust Plus** has received funding to identify "hidden" and hard to reach carers by providing an outreach service, deploying local community facilities and a converted bus.
- **Sunderland Carers Centre** has a range of targets for reaching particular groups and communities i.e. most deprived communities and overlooked groups.
- **Carers Support Centre Brigg** is working to recruit two part-time, temporary "expert carers" to act as "Carers Champions" in GP practices aiming to increase the numbers of carer identified and signposted to carers' services.
- **Warrington Housebound Reader Service** has enabled isolated carers to be identified, supplied with books and provided with relevant information.

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- **Carers Northumberland** work as a 'virtual carers centre'. They have an outreach approach with telephone support and Internet conferencing used as means of contacting carers and enabling mutual support in a rural area.
- **Lancashire County Council's Staff Carer's Register** enables staff to receive up to date information to support them as working carers. They have access to support and advice that is confidential and independent of their line manager.

Carer Awareness Raising

- **Regional Training Programme** In 2009/10 a programme of carer awareness training courses were funded for 'key workers' across the Yorkshire and Humber region as part of the Region's work to implement the 2008 National Strategy.
- **Halton** has delivered presentation to GP surgery staff and Hospital Social Work staff and distributed Newsletters, posters and other information to increase carer awareness.
- **Cheshire Carers Link Model** was developed through the multi-agency Strategy Group identifying 'carer link workers' or 'champions' across health and social care teams. The carer link workers take on additional responsibilities and are a pivotal point of contact to provide advice, information and support to colleagues. Workers are provided with training and a toolkit to help them in their role.
- **Dudley** has launched an e-learning tool called 'Carer Aware' which provides basic carer awareness training.
http://etraining.dudley.gov.uk/nolms/launch_ca01_nolms.html#
Other local authorities are planning to use this tool developed by Cylix Ltd.

Targeted health focussed interventions

The Moffat Programme (Scotland) http://professionals.carers.org/social-care/articles/the-moffat-programme,4411,PR.html
This is a fully funded programme with four pilot sites, which involves the delivery of carer awareness training to NHS staff. The good practice models and protocols developed by this programme aim to ensure that all carers who come into contact with health are:
  - Systematically identified
  - Signposted to local advice
  - Made aware of their rights and can access appropriate support to help them with their caring responsibilities

Projects receiving National Demonstrator Site funding which incorporate carer awareness raising:

London Borough of Camden and NHS Camden
The aim of the project is to improve or maintain the health and wellbeing of carers in the four most deprived wards in Camden. These wards have the highest levels of health inequalities in Camden, high numbers caring for more

than 50 hours per week and above average numbers of learning disability carers. Three of the wards have over 25% BAME populations and higher than average levels of substance misuse.

The proposed model involves:

- Raising awareness and identifying carers.
- Completing health and wellbeing checks.
- Referring to a variety of community based health promotion services, financial advice and training.
- Active case management to support carers with chosen interventions.
- Referral to GP or social care services for ongoing treatment and care.

Northamptonshire Teaching PCT

The Northamptonshire project has 4 key elements:

- Joint planning and commissioning
- Professional awareness and development
- Information strategy
- Healthier carers/carers' services.

Key aspects of the project include:

- Building on existing initiatives including Carers Assessment and Support Workers in acute hospital and other settings, personal budgets, support for young carers, single assessment process, Caring Northants website and Wellbeing teams.
- Dedicated role of Carer's Health Lead, to raise the profile of carer's issues, co-ordinate current initiatives and lead on project management and joint carers commissioning post.
- Carer Assessment and Support Workers within primary care settings to improve identification of and support for carers in those settings. These staff have a dual role, to support professional development as well as provide direct carer support.
- Information strategy extended to include good healthcare information for carers and professionals.

Swindon Primary Care Trust (PCT)

Swindon PCT hopes to build upon progress so far on increasing support for carers within the NHS by:

- Developing a suite of carer pathways that recognise differing routes into the NHS and individual carer experiences, e.g. sudden onset illness, end-of-life caring situations etc
- Developing referral protocols within and between primary and secondary care, mental health services, and joint community teams
- Creating a 'carer liaison' team and volunteer 'carer liaison roles', enabling proactive identification of carers to encompass out of hours periods
- Increasing the number of 'carer leads' roles within teams and partner agencies
- Developing modular training for clinical, nursing and frontline staff

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- Developing a 'carer aware' accreditation system enabling the achievement of different levels of support for carers to be recognised, and user to inform the development of further good practice
- Audit of assessment and referral forms used within NHS settings and piloting of alternative documentation.

3 Themes and issues

Carer Information and Identification

• Format of information for carers

Many approaches exist to the format of information provided for carers. See Paper 3 for existing good practice in York, and the current work of the Carers Information Group.

• Carer 'turnover'

There is a high proportion of carers who are new to caring every year, and a need to ensure they have access to relevant information.

• Carer identification

A distinction between carers who have low level needs and those with higher level needs may be helpful in targeting information provision to aid carer identification of those carers who are most in need.

• Carer Awareness Raising

The potential of e-learning tools is already demonstrated within the Adults, Children & Education Directorate (ACE) -see paper 3 for good practice examples, and details of current work. York Carers Strategy group agreed in October 2010 to implement the first stage of a Carer Awareness Raising training proposal.[8]

Multi-agency issues

• 'Whole area' working

A number of areas have implemented this approach featuring an explicit multi-agency commitment to carer identification and care awareness raising.

• Carers champions

Some areas have implemented an 'official' system of carers champions across health and social care teams and organisations

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[8] 'Carer Awareness Training – proposal for resource to be part of the Carers Pathway' paper presented by Frances Perry, Carers Strategy Manager, to York Carers Strategy Group meeting, October 2010.

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CYC related issues

- **Corporate approach to supporting carers**

  Carers are local citizens whose needs can be supported across CYC Directorates and local communities. Embedding a 'carer aware' approach into the work of CYC will encourage efficient use of resources.

- **Localism and area based working**

  Including carer information and identification work in the Areas Based Working pilot will help to target older carers, and carers looking after older people, which is an emerging theme.

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Appendix 1

(Please note that this is anecdotal evidence collected by Anthony Pugh, Regional Project Manager, Yorkshire and Humber Region. It has been widely shared, but is not formally validated.)

Developing and Implementing Services for Carers

Success Factors

- Political support – lead member for ASC also the carers' champion

- Senior management support (from Chief Exec level)

- Named carers' champions from health include lead clinicians

- Engagement with carers at all levels

- "Carers" an item on all meeting agendas

- Absolute commitment to working with carers

- Joint commissioning of carers' services

- Dedicated post (jointly funded) for carers

- Carer lead officer has control of carers' budget

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Appendix 2

Sources of information about good practice

1. 'Implementing the Carers Strategy in the East Midlands – a toolkit to support self-assessment and compendium of good practice'. First Edition, November 2009. Author Paul Mansfield

2. 'Good Practice Guide for Carers October 2008, North West Carer Leads Network'. ADASS

3. Information by phone and email from Yorkshire and the Humber Regional Carers Leads network members; Tony Pugh, Project Manager - Carers Strategy Yorkshire and the Humber.

4. Information supplied by York Carers Centre and PRTC regional network.

5. Princess Royal Trust for Carers website http://www.carers.org/

6. Carers UK website http://www.carersuk.org/Home

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