

Standing Commission on Carers

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Ms Ann Radmore
Chief Executive
SW London PCT Cluster

By email

29 December 2011

Dear Ms Radmore

Re. Fact-finding visits on supporting carers effectively

As you are aware, the Standing Commission on Carers, in its advisory role, was asked by the Minister for Care Services, Paul Burstow to undertake a series of fact-finding visits in 2011 to local areas to inform the Commission's advice to Ministers and to the shadow NHS Commissioning Board on supporting carers effectively.

This series of visits has now been completed and as Chair of the Standing Commission on Carers, I would like to thank you and all staff and carers involved for hosting a visit and for giving members of the Commission a warm welcome and for a varied and interesting programme. We predominantly valued meeting front-line staff as well as senior managers and particularly carers and it was thanks to you and your staff that we were able to do so and hear about their experiences, many of which were very positive.

Even though the programme for most visits concluded with a session when we gave general feedback and some impressions, some of you were keen to receive this in writing, so attached to this letter is an Annex depicting what we

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found, in general, to be working particularly well, what is working less well, some challenges and some opportunities. Also included are issues raised by carers and some general examples of good practice around the country.

It is also the Standing Commission's intention to hold a thematic day in the New Year to discuss policy and practice issues around support for carers and to share both key messages arising from our current series of visits and your own experiences. I therefore want to take this opportunity to invite up to five people from your area to include a senior manager from the council and one similarly from the PCT, a representative from your local voluntary sector and two carers. Travel expenses for carers attending on the day will be paid by the Secretariat to the Standing Commission. A member of the Secretariat will contact you early in the New Year to inform you about further details ie. the date, time and the venue.

I have written in similar terms to Bruce McDonald, Chief Executive of the Royal Borough of Kingston and am copying this letter to David Smith, Director of Health and Adult Services, Kingston PCT.

Yours sincerely

A handwritten signature in cursive script, reading "Philippa M. Russell". The signature is written in dark ink and is positioned above the printed name and title.

Dame Philippa Russell DBE
Chair, Standing Commission on Carers

ANNEX

General Feedback from Fact-Finding visits undertaken in 2011/12

Issues raised by carers:

- Situation for carers improving but still vast challenges
- Services not joined up
- Services being reduced due to funding reductions, including availability of respite
- Worried that they will not be able to influence the outcome of budget challenges
- Practical support to enable carers to participate in planning of local provision eg. meeting costs of replacement care
- Lead time of being assessed for support services can take a long time; assessments also not undertaken properly and long delays in hearing of outcome
- Significant problems about getting into the system, though 'lucky ones' full of praise for help then received; other carers questioned why it had taken so long to 'spot' that they were carers
- Loss of carers' allowance at retirement age
- Anxiety about shift to direct payments and personal budgets
- Lack of infrastructure to assist with and better communication about direct payments and personal budgets for cared for person. In one area, they were perceived as a good 'tool', but high amount of paperwork involved and better explanation required. Also no 'imposition' of personal budgets
- Medical profession unwilling to involve carers and recognise them as partners in care – particularly mentioned in relation to parent carers of young adults with mental health problems
- In some areas, services provided to parent carers and to siblings of disabled children working well
- Self-funding carers still often lack access to advice and information from statutory bodies
- Concern about uncertainties in future funding of carers' networks and support
- Overwhelming worries about transition from children's to adult services
- Young carers' role and views being taken seriously - often excluded from meetings and discussions about the person they look after; some also anxious about family being split up
- Young carers indicated that subject of caring should be discussed more in schools; also want more respite for person cared for

What is working well

- Strong commitment to working in partnership with carers
- Active Carers Partnership Boards in several locations, with inclusion of Job Centre Plus representative in one area
- High level awareness of carers' issues and commitment to them by council and external agencies
- Interesting and innovative approaches to providing short breaks and respite care
- Various young carers' initiatives, including 'Hidden Lives' scheme and young carers leads in each of GP practice areas in one area
- Link between welfare and wellbeing and appointment of a benefits and financial adviser by council
- Protection of former carers' grant resources
- Embedding carers' agenda across hospitals, including involvement of carers in discharge planning
- Strong local voluntary sector with influential carer groups, including in learning and take up of benefits
- Carers really valued the 'Shared Lives' service for people with LD
- In terms of future planning, home care contracts moved to outcome-based purchasing.

What is working less well

- Early identification of carers known by LA and NHS
- Carers' assessments:
 - Not always proportionate
 - Often not offered until crisis occurs
 - Often joint with looked-after person, rather than on an individual basis
- What exactly constitutes as a 'short break' and wide variations in their availability
- Limited infrastructure to support personalisation and communications strategy required to reassure carers, eg. that the direction of travel is about personalised services that meet individual needs, not just personalised budgets
- Perception among carers that direct payments for people they care for have too many restrictions
- Supporting carers to stay in or return to employment
- Effective involvement of LA in the development of Clinical Commissioning Groups (CCGs), particularly where CCGs cover more than one LA area and with a number of PCTs
- GP engagement with young carers
- Young carers excluded from discussions about person they care for; many isolated from help and respite
- Resource decisions having clear impact on carers eg. reduced entitlement to breaks, review of day services and new charging policies

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Challenges

- Integration between services
- Communication between different parts of the system and carers themselves
- Developing a menu of short breaks for the full spectrum of carers
- Commitment / engagement from GPs to prioritise carers' needs both in individual practices and in commissioning support
- Preventative work with young carers to avoid escalation of problems
- Identifying young carers, particularly from seldom heard of BME groups
- Identifying young carers caring for parents with substance misuse
- Encouraging flexibility in the local employment market, particularly in times of increasing financial pressure
- Tackling isolation and loneliness, particularly noted in respect of those caring for people with dementia, but others as well
- Historical reliance on well-funded voluntary sector
- Supporting carers and cared for people with information
- Out-sourcing functions with neighbouring councils without creating fragmentation and complexity

Opportunities

- Identifying more 'hidden' carers through community initiatives
- Harnessing clear energy of carers and involvement in thinking and provision solutions
- Publishing and promoting ways for carers to have a say and influence and shape change locally
- Focusing on early intervention and prevention
- Innovative provision of services for use by personal budget holders in line with the finding of the carers' demonstration sites
- Supporting carers' access to further and higher education and employment at all stages of life
- Encouraging Clinical Commissioning Groups (CCGs) to consider how they will commission support for carers in the new clinical commissioning agenda
- Use of QIPP to 'push' carers within NHS ie. promoting benefits to the NHS of supporting carers
- Face-to-face support for carers on wards
- Named lead on young carers in each school
- Encouraging joint working across statutory bodies and agencies in providing support to young carers
- Influencing Health and Wellbeing Boards and Healthwatch

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Good Practice examples

- A GP carers' prescription scheme commissioned by PCT and delivered in partnership with local voluntary organisation. A scheme whereby when GPs identify a carer, they can either give the carer a prescription or they can fax a prescription to the voluntary organisation, who will arrange an assessment of the carers' needs including respite of a few hours a week or perhaps a short break. The scheme has been evaluated and shown to maintain carers' health and wellbeing, making them feel less stressed, better informed, more relaxed and in receipt of more help. This is a model, that might be usefully considered by Clinical Commissioning Groups to reduce carers' ill health and unplanned admissions of the people they care for.
- Members of the local independent charity viz. Carers' Resource attend the ward for the elderly at the hospital during visiting hours to identify carers and offer emotional support. Carers are asked whether they will complete a 'passport' for the person cared for on admission, where personal and specific patient details to enhance the respect and personal care received, are included.
- Carers Emergency Response Service - with up to 72 hours of 'sleep-in' time to enable exhausted carer to continue caring. Plans for GPs to directly access this service on behalf of patients.
- Local council provides some useful carer specific services such as the emergency card, training in lifting, telecare and readily deployable relief care.
- Council's JSNA held up as a 'template' by the Kings Fund.
- A Carers Emergency Support Service (CESS), including a carers' 'emergency card' for all carers registered with the council, to be carried at all times, which identifies them as a carer and who to contact in the event of an emergency 24 hours a day, seven days a week.
- An innovative extra-care housing supporting older parent carers and adult children with LD, to live together.
- A Partnership for Older People project (POPP)] – a partnership between the Council, the PCT, the third sector and older people, which went 'live' in 2006. The programme has developed a robust working partnership that extends beyond this and includes a range of other service providers including fire and rescue, police, libraries, community matrons, community pharmacies and others. It is 'community facing' and is a complex and ambitious, person-centred programme, led by the needs and aspirations of older people.
- A robust JSNA specifically on carers in place as an ongoing iterative process, web based analysis of local issues that will be kept up to date
- Young Carers service 'knitted into' other services eg. youth service and education and welfare. Strong disability forum and children's charity. Inclusive 'school awards' underpins this approach.

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