Written submissions received for the London Assembly's investigation into home based social care for older Londoners

(Part 2)

Sub016

London Borough of Richmond Upon Thames

We have chosen to answer only the questions below:

3. What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?

As a funder in South West London we find an ongoing challenge to be the capacity of service providers to deliver the volume of homecare required in this borough. We are meeting these challenges through improved contracting processes and market development (particularly in the context of personalisation and self directed support) and good partnership working between our in house brokerage team and care agencies. The capacity issues arise due to the affluence of the borough (which often prevents care workers from being able to live locally) and the geography which makes transport challenging for care workers.

4. What impact do you think the proposals in the new Green Paper on long-term care could have on home care services for older Londoners?

We don't anticipate that the proposals will have an impact on demand. However, dependent on which funding model is taken forward we anticipate an impact financially on older Londoners, funders and service providers.

6. How effective is joint working between home care services and other services such as NHS Services for older people?

Within the borough we have four integrated locality teams which bring together health and social care professionals working in the community. Whilst this involves close joint working between social workers/care managers and community health professionals, there is limited direct joint working between commissioned homecare (i.e. from home care agencies) and health services.

Please could you clarify for me how this information is intended to be published (as mentioned in your letter)?

Kind regards

Sarah

Sarah Broad
Service Development Officer

Sub017

London Borough of Wandsworth

Dear Mr Cheeseman

Call for views and information: Investigation into home based social care for older Londoners

Please find my comments on the above following receipt of the letter from James Cleverly London Assembly Member.

Wandsworth has considerable experience in this area which we have drawn on in my responses below.

- 1. What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?
- One of the major areas of concern is the availability of information and advice to enable older people to make informed choices on how their needs can be met. This goes beyond Home Care and the Council and NHS Wandsworth have this area of responsibility as a key priority under development.
- 2. What good practice exists in providing home care services that meet older people's needs?
- Wandsworth Council maintains a List of Approved Home Care Providers; all of whom have to be registered with the Care Quality Commission and deliver care to an appropriate standard.
- Service Users who are supported by the Council following an Assessment of their needs and eligibility are offered the Council START Service (Short Term Assessment and Reablement Team) initially to determine how their needs can best be met to promote their independence and well-being.
- If, after a period of up to 6 weeks, it is determined that on-going Home Care Support is required this is agreed with a suitable Approved Home Care Provider.
- The Council also has an agreement with our local Age Concern who maintain a list of Home Care Providers under their Agency Information Service.

This has improved beyond recognition over the past five years but the age-old problem of health care being free at the point of delivery and social care being subject to a means-tested contribution for the most part can make the situation confusing for older people and their carers. The consultation on funding in the Green Paper may well need to address this situation.

I trust this response will be of interest and look forward to seeing the final Report.

Yours sincerely

Councillor James Maddan
Cabinet Member: Adult Care Services

London Visual Impairment Forum

Investigation into home based social care for older Londoners:

Who are we?
The London Visual Impairment Forum (henceforth LVIF) comprises locally based groups and national charities such as RNIB and Guide Dogs for the Blind, which work with and for blind and partially sighted people in London

We are delighted to have this opportunity to become involved with the policy making process in London and would wish the following to be taken into consideration.

Q1 What difficulties do older Londoners face in accessing home care services that meet their needs?

It is important to note that around 90% of blind and partially sighted people are aged over 60 years of age. It is clear that this group is not able to receive the level and the type of care they actually need.

- An example of this is a visually impaired person, called Doreen, who needed a person to clean and general tidy her home. However, this is type of support on its own, is not eligible under the FACS criteria.
- Equipment is also available to enable visually impaired people to maintain independence at home, which can help avoid the need for home care. For example, talking kitchen scales and microwave ovens assist with cooking and talking scanners or large screen magnifiers can enable visually impaired people to access their own correspondence. However, this equipment is not usually funded by social services.
- Many blind and partially sighted people are at risk of poverty because of difficulties in accessing welfare benefits. Isolation and social exclusion is experienced by many because of mobility difficulties. Both these factors can increase the likelihood of depression and falls and need for more costly treatment and care.

Doreen's inability to obtain the support she needs and the limitations on funding for equipment indicates that the whole assessment process needs to be looked at, if matters are to be improved.

Last year's CSCI the report summed up the problem faced by many blind and partially sighted people who experience, "…inadequate and unduly standardised assessments and neglect…" Assessors are not aware of the many and differing needs of blind and partially sighted people and do not provide an assessment that looks at all the needs of an individual as a whole.

Q2 What good practise exists to meet older people's needs?

Examples of good practise are most likely to exist where the various agencies and services work most closely together. This is enhanced where boroughs are prepared to show a greater level of flexibility in terms of how they define the needs of a blind or partially sighted person.

In the borough of Kensington and Chelsea all registered or register able blind people are automatically considered as a having a moderate need, according to FACS criteria, and will therefore receive a visit and a care assessment.

LVIF is concerned that some boroughs have raised the eligibility criteria to those that are critical or substantial only. LVIF believes that those with moderate needs should also have access to social care, in order to prevent deterioration in independence and well being that will eventually lead to higher care costs in the long term.
LVIF recommends that there is consistency in eligibility and assessment across London.

Q3 What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?

With ever more scarce resources in the public sector it is important to note the increasing number of older people and hence the increased pressure on the system. Part of the answer could be to look at policies which support a 'preventative approach' in other words ways in which a person is supported to remain in their own home by **all** local resources. Other bodies such as local societies for the blind often deliver services on behalf of local authorities that help prevent the need for home care. Smaller local groups, such as some of those within our membership, are often best placed to offer support, however, these are often the groups who fall victim to the current awarding policy. Particularly in regard to the policy of competitive tendering, which often favours larger organisations that have the ability to compete but may well lack the local contacts and expertise.

Q4 What impact do you think the proposals in the new Green Paper on long term care could have on home care services for older Londoners?

LVIF recognises that a thorough review of the funding of social care and support is needed, so the system it is sustainable and fair in the long term. However, the proposal of 'bringing together funding streams', particularly the suggestion of the ending of attendance allowance (AA) is causing concern. This benefit as well as Disability Living Allowance (for people who received it before their 65th birthday) was introduced to meet the extra costs of disability i.e. not just care. Any reform of the care and welfare benefit system needs to take the hidden costs of blindness into consideration or this change will cause people who are already living on low fixed incomes further hardship and distress.

It is clearly it is important that people on the lowest incomes do receive support, however, at present, people who have built up moderate savings are penalised because they face care charges. This needs to be addressed through the funding scheme decided upon for the ‘National Care Service’ in the government’s green paper.

Q5 what is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help

LVIF believe that the Mayor could play the role of advising councils of good practises such as those mentioned above.

We also believe that the Mayor, as the representative of London's Government, has a role to play with government at national level. The Mayor's influence could be applied to encourage government to adopt recommendations of organisations that represent visually impaired people's views such as LVIF and RNIB for instance:

- Consistency of provision across London and the UK of all care services including the eligibility under the FACS criteria.
- Resource allocation between health and social care:
  Recent years have seen considerable sums being provided for health care but by no means the same level of commitment shown towards social care including home care services. However, it is clear that it would only take a small shift in funding policy would greatly improve the experience of older blind and partially sighted people and other disabled people, as many are not receiving the support at home that they need.

LVIF applauds policies aimed at prevention and believe that if visually impaired people received both appropriate equipment and care at an early stage this would lessen the need for more intense and costly home care support in the longer term.

LVIF September 09

Federation of Irish Societies

About the Federation of Irish Societies (FIS).

FIS is a national umbrella for the Irish voluntary sector operating across the UK. We currently have 140 member organisations of which 30% are London based and most of which provide a range of frontline support and advice services to vulnerable Irish people and other BAME groups.

We provide capacity building support to our member organisations in areas of service development, governance and … We aim to address health inequalities and social exclusion faced by Irish people in Britain and work constructively with key decision and policy makers at a national, regional and local level. We raise awareness of the specific needs of the community, the barriers to accessing statutory and mainstream service provision and the positive impact of partnerships between the Irish community sector and
The statutory and third sector.

About the Irish in London:

Age and life expectancy:
The age profile of the Irish community in London is an older one with significantly higher numbers in the post pension and pre-pension age group. 20% of the white Irish population in London is aged 65 or older.

In Britain as a whole the percentage of Irish people aged 50 and over (51.5%) exceeds the White British population (35.2 %) and non-white minorities (14.5%) at in all age bands above 50 except for 85 +. As with most other groups the numbers of women exceed men.[1]

Disability:
Limiting long term illness and self reported poor health is higher among Irish people compared to the white British population at all ages except for women over 65. The greatest differences are in the 16-64 age band and among men[2].
This reflects the findings of the 1999 Health Survey for England which demonstrated the prevalence of LLI among Bangladeshi, Pakistani and Irish men to be 30 –65% higher than in the general population[3]

Methodology for this response

FIS's policy work is evidence based, informed by the views and real life experiences of Irish people across London and the UK and of our members, the Irish organisations that

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[1] http://www.statistics.gov.uk/CCI/nugget.asp?ID=874&Pos=1&ColRank=2&Rank=1000
[2] Source: 2001 Census. Crown copyright. Standard Table S107
[3] Erens at al 2001

are set up to serve them. For this London focused consultation response we collected evidence through:

- Focus groups with Irish pensioner groups in Camden
- Targeted questionnaires to Irish voluntary and community services working with older Irish people in Camden, Hammersmith and Kilburn.

Consultation Questions

1. What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?

FIS have found that older Irish people across London have had very varied experiences in accessing home care services. It was almost unanimously agreed that referrals for home care services made by social workers for an older person in hospital it resulted in a significantly quicker process than referrals made by community and voluntary agencies, regardless of the degree of need. The time lapse between referral and assessment and between assessment and service start up also varied between boroughs again regardless of the level of presenting need.

Those respondents who had experience of working with a Collaborative Care Team reported much a speedier process from referral to assessment and services being put in place. This would therefore suggest that a more systemic approach with key agencies working collaboratively would support better access more generally across boroughs.

Amongst those who were not receiving home care services most reported being unaware how they would access services if they felt at some stage they needed them. The majority felt they were most likely to seek advice and information from the voluntary sector services with which they are more familiar. The role of the voluntary sector or of a family member or friend in supporting access was particularly noted. All respondents who receive home care support cited the need for their support worker or family/friend to advocate on their behalf in the assessment stage and later if there were aspects of the service that needed to be improved. Problems consistently arose where there was no advocate in attendance at the assessment,

2. What good practice exists in providing home care services that meet older people's needs?

There were many examples of good practice in the provision of home care services mainly in relation to the positive experiences of having a particularly good member of staff provide the home care services and one who attended on a regular basis.

Where NHS services such as district nurses can mean that older people often have different staff arriving each day this is off set when the homecare provider is the same member of staff each time. Continuity of staff was considered to be particularly important for older people. They felt more confident and comfortable about receiving the service, less vulnerable and intimidated and felt more socially engaged than when a range of staff with no personal connection to them arrived each day to undertake the tasks.

The less positive feedback included widespread reports of carers being rushed, not completing all the tasks as set out in the care plan or of poor quality of service. In the

worst instances carers failed to turn up leaving the older person with unmet needs and feeling particularly vulnerable. In these instances it was the local Irish community support service who usually stepped in to ensure that they had their immediate needs met.

Most respondents who receive home care services reported feeling vulnerable and apprehensive about making a complaint in case they were treated badly by the staff as a result. They had almost all had experience of that at some stage. Complaints were only made in situations where there was a family member, friend or support worker to advocate on their behalf reinforcing the need to ensure that older people have sufficient advocacy support either through carers or trusted community services.

In a number of situations we found that rather than complain, carers would often take on some of the tasks which fell under the home care arrangement. This included a friend who took on to do an older persons laundry as a result of a number of garments being ruined by the home care provider. Animosity from staff towards a carer or advocate who had made a complaint was frequently reported.

Best practice reported by advocacy and community support services as well as feedback from older people included:

- Good time keeping
- Continuity of carers
- Well trained carers
- Where the cost to older people was more manageable for them.

3. What challenges are London's service provider facing in providing home care services for older people? How can these challenges be met?

Frequent staffing changes, low level commitment from staff receiving low salaries for their work, uneven levels of funding from social services and different structures in social services across different boroughs which result in a variation in the level of engagement between the home care provider, social services and the older person and their formal or informal advocate.

The possibility of basic care standards, shared assessment processes and improved joint working structures across health and social services would have a significant impact in terms of raising standards across postcodes and increasing the interface between the variety of service needed to support older people remain independent with support.

4. What impact do you think the proposals in the new Green paper on long term care could have on home care services for older people?

The Green paper proposals strike a very positive note in terms of its intentions and aspirations for improvements to older people's services. The more systemic approach whereby there is a greater emphasis on seamless provision through joint agency co-ordination is welcomed as is the aim to reduce the post code lottery which makes some older people receive a much better service than others as a result of the borough in which they reside.

That the proposals rule out paying for a universal basic service out of taxation and imply the introduction of a voluntary or compulsory insurance scheme has had a mixed reaction amongst our members however there is some acknowledgement that a mix of arrangements might be more sustainable. The overwhelming preference is that older people do not have to sell their homes in order to receive care and that carers are at no disadvantage as a result of providing the critical support to their family and partners.

5. What is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help ensure older Londoners can access care services that meet their needs?

The Mayor could establish a charter of standards in home care provision which all London local authorities could sign up to. This would encourage basic standards across different postcodes, greater sharing of best practice and a more systemically structured approach to home care provision.

6. How effective is joint working between home care services and other services such as NHS services for older people.

It was universally reported by respondents that where NHS and social care /home care providers worked closely together the quality of service was significantly better. Examples demonstrated the ability of agencies to co-ordinate successfully and ensure a more seamless service for the older person.

System failures included insufficient communication between the hospital transport services, older people and the NHS clinics and in several instances the older person arrived long after the appointment was due. This lack of coordination or in many instances availability of transport services was the primary source of difficulty.

In other situations older people reported not having had their home care services early enough in order to be prepared to then go for a hospital appointment. The pressure on GP's time meant that many older people were unaware that GP's can undertake home visits alleviating the need for them to be seen on ground floors.

Princes Royal Trust for Carers

Thanks for your message and apologies for not having responded sooner to your letter. Our responses are below:

1. **What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?**

   - There are often difficulties around finding services that are flexible enough to meet the varied needs of service users and their carers. Often it's a 'take it or leave it' service which is fine for some but not all. Services need to be tailored to individual needs and, whilst this can be done, it costs more and is often not available for that reason.

2. **What good practice exists in providing home care services that meet older people's needs?**

   - Crossroads provides a model of services developed around people rather than people having to fit into the service on offer. Often the smaller services that have been developed to meet particular needs will have good results – specific services for people with dementia for example.

3. **What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?**

   - There are some challenges around personalisation and the loss of secure funding in terms of contracts etc will put pressure on providers. In the short term it will be difficult for them to plan and develop services with such an uncertain financial situation, although in the long term there will hopefully be services available that are more responsive to individual need. Funders need to be aware to the need to support and sustain good quality services through this transitional period, or the outcome will be poor with little choice of service provider left for people who have been given individual budgets.

4. **What impact do you think the proposals in the new Green Paper on long-term care could have on home care services for older Londoners?**

   - It's too soon to say what the impact will be on home care services as these will still be needed whatever the funding system or assessment process is.

5. **What is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help ensure older Londoners can access care services that meet their needs**?

   - Perhaps the Mayor's role could be to ensure that all Londoners have access to the same kinds of services, assessments etc – it's a very patchy system across London at the moment and the whole 'postcode issues' is particularly relevant

here – people's access to services may change dramatically just by moving across the street from one borough to another.

6. How effective is joint working between home care services and other services such as NHS services for older people?

- Again this is quite patchy and depends on the borough. When it works well it can make a tremendous difference to people's lives

I do hope that this is helpful.

Best wishes

Moira Wilkinson
Development Manager

Sub021

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- Stroke Association
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Submission from The Stroke Association to the call for views on: Investigation into home based social care for older Londoners

About Stroke

An estimated 150,000[4] people have a stroke in the UK each year and 67,000[5] deaths are attributed to stroke. In London stroke is the second biggest cause of death and the most common cause of adult disability. More than 11,000 people having a stroke are admitted to London hospitals each year – one in six dies and more than 6,000 are left with an impairment following a stroke.[6] Around half are left dependent on others for everyday activities.

With the increase in contributory conditions such as diabetes and obesity in conjunction with an ageing capital and a growing BME population, and improvement in stroke survival, disease incidence and prevalence is inevitably going to increase with more people living with disability.

About The Stroke Association

The Stroke Association is the only UK wide charity solely concerned with combating stroke in people of all ages. We fund research into prevention, treatment and better methods of rehabilitation and help stroke survivors and their families directly through our website and national helpline.

We provide a range of community services that focus on supporting people to regain a life after stroke. This includes support to people with communication difficulties as a result of stroke, providing advocacy, advice, family and carer support, information services and welfare grants. In addition we campaign, educate and inform to increase knowledge of stroke and act as a voice for people affected by stroke.

The London Context

Healthcare for London responded to the call to improve stroke services and survival rates by proposing a reconfiguration of stroke services, based on the National Stroke Strategy (2007)[7] framework. The Stroke Strategy for London (2008) emphasised the

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[4] ONS (2001) Office of National Statistics Health Statistics Quarterly (12) Winter 2001 "Stroke incidence and risk factors in a population based cohort study"; Scottish Stroke Care Audit 2005/2006.

[5] BHF (2005) Coronary Heart Disease Statistics. British Heart Foundation

[6] Healthcare for London (2008) Stroke Strategy for London

[7] Dept of Health (2007) National Stroke Strategy

importance of quick access to specialist acute care and high quality community rehabilitation and long term support.

In the last two years The Stroke Association has doubled its reach to Londoners. We now provide support to families and carers in 18 out of 33 boroughs, helping at least 1000 people per year to improve their quality of life after stroke and stay in their own homes. In the next five years we aim to provide support to people affected by stroke in every London through our comprehensive range of services.

We are delighted to be able to respond to this timely scoping work. You are particularly interested to getting responses to some or all of the following questions:

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- What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?
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- The effects of a stroke can leave a person with a range of physical and communicative challenges. From paralysis; sensory loss; speech problems; incontinence; swallowing; memory problems or Agnosia (loss of awareness), supporting a person with these challenges is complex and can demand a high level of personal care. The type of local authority care to support these disabilities can include meeting everyday living needs; physical needs: emotional and well-being needs; social needs; communication and cognition needs; financial, legal and care needs; re-enablement needs and carer needs. The services required include personal care, meals on wheels, respite care, aids and adaptations as well as the opportunity to attend day centres.
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- Many of our service users describe the isolation and helplessness they feel when they leave hospital, in their words 'a black hole'. They have reported the critical delay in arranging adaptations and aids, and home care services. A week previous to the stroke, their husband or wife could access the first floor toilet or climb the three flights of stairs to their home. After discharge this activity was not possible and delayed a return home with any dignity or ease.
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- The service users we work with have a range of experiences of personal care. Many have reported frustration when the personal carers constantly change. Consistency is really important to a stroke survivor and their families. It can take time to learn how to specifically communicate with a stroke survivor. The same carer each day would enable a respectable level of communication to develop which would give confidence and dignity to the stroke survivor. Sadly this is not happening across London.
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- For stroke survivors to improve, they must do as much for themselves as possible, however slowly. The small amount of time given by the personal carer can undo the important rehabilitation work of the stroke survivor. This then accentuates the dependent situation they are in and can seriously damage the prospect of long term improvement.
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- Service users in London have reported that personal carers have a clear remit and are often not flexible. Stroke survivors have a range of disabilities and each need attention. Some fall outside the remit of basic care (e.g. toe nails can not be clipped or a light bulb cannot be changed)
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- What good practice exists in providing home care services that meet older people's needs?
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- The Stroke Association provides a range of 'Life After Stroke' services. Contracted by the PCT or Local Authority, the services are community based, providing support to stroke survivors and their families in their own home or community. The services are specific to the needs identified by the stroke survivor and family.
- All services provide emotional support. Some act in a key worker capacity, providing information, advice, support and advocacy, joining up social and health care provision. Other services focus on giving communication support to enable the stroke survivor to develop new skills in communication. This renews confidence and recovery of independence. Some services offer basic financial support and help people get back to work. Across London we currently run 22 services within 18 boroughs and support over 1000 clients a year.
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- Case Study:

Mr O is a stroke survivor and is quite disabled. He moved into a flat alone with very little assistance from social services or housing. On the Stroke Association Co-ordinator's first home visit to the client in February it was noted that he did not have basic essentials such as a bed, fridge or freezer, washing machine, window furnishings etc. Over 3 months the Co-ordinator was able to assist the client in different ways. They:

- arranged for a handyperson from the Handypersons Scheme to visit to hang his blinds and curtains
- liaised with his GP with regards to his low mood
- assisted him financially and he was awarded Incapacity Benefit
- arranged for a workman to sort out the windows which could not be opened
- contacted Lewisham Disability Coalition to visit re: his full benefit entitlements
- followed through an application which the Co-ordinator had submitted and Mr O received a fridge freezer and washing machine from The Stroke Association's welfare grant scheme
- completed a Community Care Grant Form for a bed and a cooker.

- We aim to ensure all stroke patients and their families receive written information and support across London immediately after having a stroke. Currently information packs describing all the aspects of living with a stroke are given out to all stroke patients and families who access our services in London.
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- What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?
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- All the services run by the Stroke Association are funded by either the PCT or Local Authority. The National Stroke Strategy allocated funds to Local

Authorities to commission community stroke services as part of the care pathway. Some Local Authorities (e.g. Waltham Forest and Kingston) have used these funds to meet the Stroke survivor's needs. Some have jointly commissioned services with the PCT (e.g. Camden). Most services are funded for up to two years and only offer either a key worker service or a communication support service. However to maximise the rehabilitation outcomes, ideally the stroke survivor and family may need both to facilitate improvement.

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- In our experience many London social service commissioners are not familiar with impact stroke has on people's lives and therefore do not appreciate the type of complex support a family may need. In some boroughs it is extremely difficult to identify where the ring fenced funds have been spent.
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- What impact do you think the proposals in the new Green Paper on long-term care could have on home care services for older Londoners?

The Stroke Association welcomes the publication of the Green Paper and the recognition by the government that major reforms are required to the delivery and funding of care and support. We welcome the encouragement of a debate on the proposals.

We are currently examining the Green Paper and identifying the key issues for stroke services and for stroke survivors. We will identify where we feel it is most appropriate to respond.

We will examine the six elements that the Government feels should be expected from a National Care Service and the three areas where change will be required to see if they meet the requirements of stroke survivors and their carers. We will also look at whether they fit with the National Stroke Strategy for England. We will also look to see if they are likely to help deliver our proposed needs based model for long-term support.

We are concerned that the Green Paper funding proposals focus mainly on residential care for the elderly and give little explanation of how those under pensionable age with a long term condition like stroke will be funded or what sort of service they can expect. There is also little mention of the eligibility criteria for services such as aids and adaptations that are important to stroke survivors. Without these details it is difficult to assess how stroke survivors will fare under the new system.

Stroke survivors do not all face the same circumstances and hence there may not be one funding option that The Stroke Association can support on behalf of stroke survivors. Although the majority of stroke survivors are elderly, 25 % are under 65 and some of these may require residential care and are unlikely to have any savings. They may have mortgages and other financial commitments. Others over pensionable age may have savings. What is important is that any system recognises the different needs and circumstances of stroke survivors particularly those who may have a stroke at a young age and require support over a long period of time but have limited income and possibly no savings.

At this stage we feel it may be inappropriate to recommend any one of the funding options as being the best option for stroke survivors. However, we will listen to the

views of stroke survivors and others and look to see if there is a consensus amongst other charities working with people with conditions similar to stroke.

The Green Paper raises the possibility of integrating some disability benefits such as Attendance Allowance into the social care system. We would want to see how this would work in detail as it is a valued source of income for some stroke survivors.

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What is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help ensure older Londoners can access care services that meet their needs?

We would invite the Mayor to adopt a vision for the long-term care of Londoners living with chronic illness and disability. A helpful start will be to engage with The Stroke Association and other organisations to ensure that the investment made through Local Authorities is monitored and is used effectively to deliver high quality services.

How effective is joint working between home care services and other services such as NHS services for older people?

There is a great variation in effective support in the community. More co-ordinated services in the hospital, home and community would help people access the right support at the right time. With adequately funded, co-ordinated care stroke patients can return to an active and fulfilling life.

It is imperative the right personal support and rehabilitation should begin as soon as a person has a stroke and continue for as long as required to ensure best recovery. This includes providing personal care in people's homes. Some areas have good community stroke services, in others – none. Where supported early discharge has been arranged, this has resulted in shorter hospital stays and a better outcome in the quality of life for the stroke survivor.

Written by Lucy Hastings
Head of London Operations

- Stroke Association, Oct 2009

Mayoral Advisor on Health and Youth Opportunities

Social care options for the Mayor – response from Pamela Chesters, Mayoral Advisor on Health and Youth Opportunities

Thank you for your letter inviting me to comment on the London Assembly's Health and Public Services Committee investigation into home based social care services for older Londoners.

The Mayor believes that services to older people should be designed to empower and promote inclusion. Individuals need to be in control and make choices about the services they receive. However, current arrangements in the funding and delivery of services work against promoting choice and independence by rationing resources and offering a limited range of services only to the highest levels of need. Problems of low pay structures, difficulties in recruitment and retention and a need for greater diversity in provision all add to the problems that London faces.

1 What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?

Older people are often faced with inflexible services that fail to adequately address their needs and offer little choice. Services are often provided at a time and in a way that do not meet the needs of the individual. This can make the user dependent on how the service is delivered rather than the service promoting independence and choice. There is also a lack of transparency in services that are provided across London resulting in what is often referred to as a postcode lottery whereby services available differ from borough to borough. This runs counter to the vision set out by the Government in documents such as 'Putting People First' of services that promote independence, well-being and choice.

The Mayor believes that the personalisation agenda, individual budgets and appropriate commissioning have the potential to address these issues but there are also concerns in London around the quality of the workforce and functioning of the market that need to be addressed before real reform is possible.

The boroughs and the Department of Health (DH) recognise these problems and there are a number of important initiatives taking place based around borough and pan-London partnerships that seek to address borough delivery issues within the context of a wider London framework. The Mayor will continue to support the work of the London boroughs in the lead that they are taking in addressing this agenda.

- 2 What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?

Suppliers

Suppliers often face problems around the recruitment and retention of staff. Employment in social care occupations is often low paid and low status and is seen as a

way into the wider jobs market. Instead of staying in social care employees will often move on when new and better opportunities present themselves. This makes employers reluctant to invest in training staff. Many areas report high turnover rates for staff.

As part of addressing these issues the Department of Health is working with key delivery partners to deliver an Adult Workforce Strategy. This aims to address the key workforce priorities to enable delivery of the personalisation agenda. Steps are also being taken to support effective leadership, management and commissioning skills through the development of a Skills Academy for Social Care.

The Mayor also has a contribution to make through his work on the London Living Wage. Social care work is among the lowest paid occupations in London. Improving pay and conditions will help in improving and retaining staff.

Across London there is also a need to promote the development of smaller, more flexible service providers that are better able to meet the needs of London's diverse communities. The development of appropriate commissioning skills will help in this respect.

However, current contracting arrangements essentially pool together resources to purchase social care, providing local authorities with considerable buying power to keep down costs. Larger contracts, though, favour bigger providers with established reputations, tendering experience and financial security. Disabled people's groups often complain that the current social care economy works against smaller, more flexible suppliers and restricts choice. A move to self-directed care may help to break down this barrier and help to promote smaller, more flexible providers.

It is important that appropriate support is available to small and medium size enterprises, the voluntary sector and social enterprises to allow them to enter the social care market. This should allow greater competition and innovation in social care and encourage more community based suppliers who could more appropriately address the needs of diverse communities.

The development of new community based social care providers will also provide employment opportunities across London. Social care has long been recognised as an entry point into employment in London, especially for new migrants, but is undervalued and offers little career development or training.

Individual budgets

Mention should also be made of individual budgets (IBs) which build on what works with direct payments and are a key element in the transformation agenda. IBs have the potential to completely transform the relationship between the service user and service provider with the person using the service having the freedom to shop around for services that best meet their needs. Take-up of individual budgets is relatively low among older people and their carers. Research has shown that many older people have insufficient information about them or lack confidence in their ability to manage them.

The Mayor is supportive of efforts to improve the promotion of individual budgets. IBs have the potential to meet individual need, promote choice and help to develop smaller, more flexible suppliers. However, many older people are put off direct payments by the thought of having to deal with endless paper work or negotiating service standards. The DH could help by doing more to support organisations which provide employment

support services to older and disabled people. This would allow older people to enjoy the flexibility of direct payments while having administrative issues dealt with by support services.

Funders

There has been a growing sense of crisis in social care for some time in London and anger among older people's groups about what they see as cuts in services combined with increased charges. Older people feel that they are being asked to pay more for less.

London Councils estimate that the average unit cost of care in London is 18 percent higher than the national average. Recent changes to the Government's formula for distributing social care funding for children and vulnerable younger adults mean that London has lost out because the new formulae fails to take full account of the needs of vulnerable individuals with complex and multiple needs such as those with mental health and drug problems. They are also driven by benefit and tax credit data which have much lower take up rates in London compared to the rest of the country and population data which does not fully measure the capital's complex patterns of migration.

Despite repeated lobbying by London Councils and others the Department for Communities and Local Government and Department of Health have indicated that they have no plans to review the social care formulae. The DH has also highlighted the need to consider the wider review of social care financing and funding being undertaken by the Government. As such there is considerable uncertainty about the Government's intentions on funding.

Councils have responded to the squeeze on budgets by restricting access to services. The impact of changes in eligibility has also been highlighted by organisations such as Counsel and Care's national study on care charging and eligibility criteria. This found that older people with lower levels of need are getting fewer services. This means there is little or no support for those who are finding it hard to live independently but whose needs are relatively simple. This will affect thousands of people, although the exact numbers are not known. The burden of cuts in services is falling increasingly on carers, who are filling the gap, and on the toll on the health and well-being of older and disabled people.

3 The Green Paper

The Mayor welcomes the publication of the social care green paper. Current social care arrangements are clearly unsustainable and fail to provide the quantity and quality of social care that older Londoners deserve despite the best efforts of the boroughs. However there are a number of areas of uncertainty in the Green Paper that the Mayor would like to see clarified.

We would like to know if and to what extent account will be taken of higher care costs in London in determining appropriate levels of funding for care packages. As has already been highlighted care and living costs are higher in London than the rest of the country and this should be recognised in the level of funding that people receive. Failure to properly do so could work against the interests and care needs of older Londoners.

We also understand that as part of a national care services individuals would be assessed according to a common set of eligibility criteria. We understand that work is being

undertaken around developing these eligibility criteria. This is obviously a very important piece of work as it will determine who is entitled to support and the level of support that they can expect. Debates around funding and eligibility are difficult to fully engage with in the absence of clear criteria of needs.

4 What is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help ensure older Londoners can access care services that meet their needs?

The Mayor has no direct responsibility for social care in London. It is largely delivered by the boroughs although this increasingly involves partnership working with a range of partners including health, private sector providers and the voluntary and community sector. However, many of the issues that the London boroughs face in delivering high quality social care are regional in their nature and generally beyond the scope of individual boroughs to deal with effectively on their own.

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There is already a well developed agenda for change led by the Joint Improvement Partnership (JIP) that the Mayor is happy to support. The JIP brings together the London boroughs, the NHS, London Councils, and Skills for Care and others to help address common issues of workforce and service development, share and disseminate knowledge and information and drive improvements that will deliver the common priorities.

The Mayor already engages with the JIP. The Mayor plans to continue to make this a major focus of his engagement with the social care agenda. It is a major opportunity for the Mayor to support social care development across London and engage with key players in its development and delivery. Individual initiatives by the Mayor such as the Living Wage can however help in supporting the value placed on social care workers.

Through his health inequality strategy, which is now beginning its period of public consultation, the Mayor recognises the challenges faced by those needing social care and the burdens this can place on carers. He will be seeking to work with partners to see how these challenges can best be met.

Sub023

London Borough of Hackney

Dear Michael

Call for views and information: Investigation into home based social care for older Londoners

I am pleased to attach our response to the above call for views and information. The response focuses on the key areas of concern for the London Borough of Hackney.

I would like to take this opportunity to thank you for extending the deadline for submission of this response.

If you require any further information please do not hesitate to contact me.

Yours sincerely

Janice Wightman
Assistant Director, Adults and Safeguarding

What difficulties do older Londoners face in accessing home care services that meet their needs? How could these difficulties be tackled?

Some of the difficulties that older Londoners face in accessing home care services include the Fair Access to Care Services (FACS) criteria being set at different levels by different local authorities within London and across England. The prevention agenda places an emphasis on lower levels of home care intervention which can be beneficial and promote levels of independence for older people. There is a list of approved providers in Hackney where older people with the means are asked to pay for services; this may be difficult for some people who are just about managing and at risk of deterioration, and this contradicts the prevention agenda.

The costs for home-based social care are expensive, with the average costs around £12 per hour for some levels of support. Many people experience difficulties with cleaning, home help services previously provided help to some people living in squalor who are not able to organise and get this done themselves. In Hackney we have identified the need for a specific cost effective service tailored to lower level of needs around domestic tasks.

In Hackney our home care services are recognised as providing a high quality of service, this was recently acknowledged by the Care Services Efficiency Delivery network (CSED). Our external and in-house home care services are complemented by a high level of re-ablement services, and intensive re-ablement provision. This is to enable older people in receipt of a service following a period of hospitalisation to be independent and to find their own level of ability to live independently. The investment and unit costs for this type of service provision are high and our intermediate care service is a free service for six weeks following discharge from hospital.

We are aware that some other local authorities have experienced problems when they externalised all their in-house home care services. In Hackney we have recognised the importance of having absolute clarity about in-house services especially where long-term care, safeguarding issues and complex need are concerned. Independent home care providers in Hackney and in other local authorities can decline to take on complex cases, however, a recent procurement exercise, for the provision of specialist and cultural home care services, has identified and commissioned several high quality specialist home care providers who will work alongside the in-house service on complex cases.

What good practice exists in providing home care services that meet older people's needs?

Our First Provider Duty Team (FRDT) and First Provider Response Team (FPRT) are available and accessible and can provide an immediate response when a care package breaks down in the community, the absence of which would lead to a hospital admission or readmission in many cases. The First Provider Duty Team has had notable success in reducing delayed discharges and hospital readmissions. The provision of such services helps people to access services as well as increasing the option of admission avoidance.

The Service Specification for the externalised home care services is 'outcome focused', promoting the independence, well being and choice of the individual Service User and Carer. The delivery of such outcomes are supported by an enhanced contract monitoring framework and close partnership work between the Providers and the Council in order to achieve measurable change.

What challenges are London's service providers and funders facing in providing home care services for older people? How can these challenges be met?

Challenges which London's service providers and funders face include the prevention and preventative agenda. Preventative services cost on average £6 an hour more than standard service costs, one of our main challenges in relation to funding is to be able to gather local evidence which indicates that preventative services are a good investment. However national research indicates that when people have intensive reablement, they are less likely to require services at a later stage. In the absence of local research which corroborates national research findings in this area we have to make a business case about the level of investment required and resultant savings in the absence of local evidence which is difficult and time-consuming to gather.

Other challenges encountered by Hackney Council include individuals having the choice to stay at home with individually tailored care packages to meet their needs. Older people and those in receipt of palliative care are opting to remain at home or end their life at home. The challenges placed on home-based social services are huge in terms of human and financial resources. This is also a more expensive option than residential care especially in relation to palliative care. One of the challenges for most local authorities is to balance the intensive use of resources for home-based social services without nationally capping the amount paid to the individual.

Residential care costs in Hackney equate to approximately £600 per week where as home-based social care costs can be up to £1200per week. However in relation to the

latter the level of support provided enables a reduction in the level of need and enables the individual to become more independent in the long term.

In relation to capping the amount paid to individuals for home-based care services especially where intensive care packages are concerned we need to acknowledge that the political will precludes this option from being considered.

Our home based social services adhere to good practice and work jointly with our colleagues in the City and Hackney NHS Primary Care Trust to provide joint input.

What impact do you think the proposals in the new Green Paper on long-term care could have on home care services for older Londoners?

The new Green Paper will not have a huge impact as people are paying for services anyway which are means tested. One possible impact is where people will be even more careful with money and will think twice about using services.

The provision of Individual Budgets will change the whole contracting process as individuals will have a greater provision of choice and may not choose to use in–house services especially if unit costs are higher than in the voluntary or independent sector.

In relation to Individual Budgets and transformation, the process of getting an individual budget and the process of regulation will need to be looked at carefully especially as this may involve moving from a highly regulated care market into a largely unregulated one. However, the Council would be in the position to establish a list of 'accredited' providers to service users who wish to commission their own service under individual budgets. This list would consist of current contracted providers subject to satisfactory performance.

One possible unanticipated consequence arising from the above is the huge demand placed on Safeguarding Adult Teams especially if the incidence of abuse and poor practice increases.

What is the current role of the Mayor in terms of care and support for older Londoners? Is there anything else the Mayor should do to help ensure older Londoners can access care services that meet their needs?

To initiate and provide support for the development and procurement of the best services to meet the needs of residents. The provision of relevant strategies and policies, which provides guidance on how services should work, would be welcome.

How effective is joint working between home care services and other services such as NHS services for older people?

There is a culture of effective joint working in Hackney, with two of our divisions integrated with the PCT and a third division which is closely aligned with the PCT. However from an operational perspective we could do more in this regard, some additional work needs to be done around admission avoidance and discharge.

We have good services in place; for example, FRDT and FRPT, these are complemented by good forums for both in-house and independent providers, these forums ensure that we work well together and have good information networks and accessible training

provided by the London Borough of Hackney Workforce Development Team. This training is also available to our independent providers and colleagues in health. Our colleagues in health reciprocate by providing specialist training; there are also reciprocal training arrangements in place for induction training. However we would like to see the creation of more joint posts at a more senior level in place.

We have strong joint funding agreements in place especially section 75 agreements; we feel that they are effective to a certain level. However in our view joint budgets would be a more attractive proposition instead of having to bid for individual pots of money, we are pleased to note that the service is moving in this direction.

We have established an Intermediate Care Group, membership of which includes colleagues from health. One of the difficulties encountered is to demonstrate the effectiveness of hospital discharge and the financial savings and greater utilisation of resources arising from this. Ideally we would like a national mechanism put in place where savings resultant from an effective hospital discharge could be redirected to adult social care services.

We are considering setting up a project group which would look at the benefits of an effective hospital discharge system with particular focus on the following:

- Funding recharging mechanism – this is a complex area which requires further investigation
- Developing an Admission Prevention Project
- Defining people who need hospital admissions
- Admission avoidance – what does this entail
- Progression from FRDT to community support services
- Concept of a joint service hospital at home, this enables a quicker recovery and could be counted as one bed saved considering that one hospital bed costs in the region of £3,500 per week.

Sub024

Counsel and Care

Evidence was received from Counsel and Care dated October 2009. If you wish to view an electronic copy of this document please contact Susannah Drury, Scrutiny Manager at Susannah.Drury@london.gov.uk

Sub025

Alzheimer's Society

Dear Sir/Madam,

The case for change – why England needs a new care and support system

Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers. It is a national membership organisation and works through a network of over 230 branches and support groups. The Society has expertise in providing information and education for people with dementia, carers and professionals. It provides a helpline and support for people with dementia and carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia.

Summary

1. People with dementia and their carers need significant support and as the numbers of people increase, more people will need more help.
2. The current system of care does not deliver early intervention for people with dementia.
3. The current system of charging hits people with dementia especially hard because of the nature of the condition, the enduring nature of it and the charging regime.
4. To make independence, choice and control a reality will require:
    a) Improving early intervention in dementia
    b) Improving supply of dementia services
    c) Developing clear evidence and guidance about personalisation in the context of dementia
5.The 'balance of responsibility' for a new settlement needs to recognise that people with dementia and their families are already bearing a significant burden in terms of providing care and cost. A new settlement will only have public support if people have confidence that the state is recognising its responsibility to provide and pay for a universal level of care, apart from providing information and brokerage support.
6. There should be one system for everyone, which is age inclusive, ensuring that older people can receive the same levels of support as younger people, appropriate to their needs.
7. National consistency is much more important than local flexibility on eligibility and charging criteria.
8. A new system of targeting resources and paying for care must deliver a universal offer for all which goes beyond the assessment, information and brokerage, which is what is supposed to exist now.

1. Introduction

To inform the Government debate on the future of the adult social care system, Alzheimer's Society published the report *The Dementia Tax -Charging People With Dementia for Inadequate Care: the Case for Change* (2008). The report describes the types of services people are currently receiving in their homes and in care homes, and

how much people are contributing financially towards the cost of care. In this response we set out some of the main findings of the Dementia Tax report and also answer the specific questions put in the consultation. This Dementia Tax report is based on a survey completed by 2,364 people with dementia and their carers in England in February and March 2008 and three focus groups in Harlow, Maidstone and Vale Royal. The vast majority of responses, 2,229 (94%) are from carers, with 86 responses from people with dementia themselves.

This report puts the case that people with dementia and their carers believe that the current system of care fails to provide access to good quality care per se and that the system of charging hits people with dementia and their families particularly badly.

2. Background

There are currently 700,000 people with dementia in the UK, but this number is set to rise rapidly to over 1 million by 2025 as the population ages. One in three people over 65 will end their lives with a form of dementia. In England, 580,000 people have dementia.

People with dementia and their carers are significant users of health and social care services. As the disease process takes hold of the brain, the amount of help from health and social care services that someone with dementia requires increases, until many people with dementia require longterm care in a care home. Two thirds of people with dementia live in the community either alone or with a family member. One third of people with dementia live in care homes. In care homes at least two thirds of people have a form of dementia.

Last year a report from the London School of Economics and King's College London commissioned by Alzheimer's Society estimated the financial cost of dementia at over £17 billion for the state and families. This cost is likely to grow significantly as the number of people with dementia rises. A recent King's Fund study estimated that the cost of dementia in England will rise from £14.9 billion per year in 2007 to £24 billion (at 2007 prices) by 2026.

Despite the cost we know that there is a systematic failure to provide good dementia care and a serious look needs to be taken at where this money needs to be spent. A series of reports have found poor quality of care in care homes, people's own homes and in hospitals. Yet people with dementia end up paying significant amounts towards their care because the majority of the package of care that they receive is typically provided through local authorities and is means tested.

In England the government has recognised the scale of the challenge on dementia by announcing that dementia is a health and social care priority. The Department of Health is working with Alzheimer's Society and others to launch a National Dementia Strategy and Implementation Plan for England by the end of 2008. The draft Strategy identifies three key themes:

- Improved professional and public awareness of dementia
- Early diagnosis and intervention
- High quality care and support.

3. Major findings of the report *The Dementia Tax*

The report reveals that the current system of charging for social care is effectively a tax on many people with disabilities. Social care for people with dementia is particularly unfair - the majority of essential care comes from social services, is means tested and is required over a period of many years.

- People with dementia need a significant amount of care and support Services for people with dementia are limited and vary considerably
- **People with dementia and their carers are among the hardest hit by the current charging system**. Because the majority of the package of care that people with dementia receive is typically provided through local authorities and is means tested, people with dementia end up paying significant amounts towards their care and often for a long period of time. For example, four fifths of people are making a contribution towards the cost of care at home. Over half of people contribute over £300 per week for care home fees. Despite the amount that people pay, the quality of care is often poor.
- Charging affects people from all kinds of backgrounds, including **those on low incomes because of the means-test thresholds. In the last 10 years the numbers of people from all social groups who are having to pay for care has increased.**
- People are willing to make a contribution but only if care improves.

4. Key recommendations of the report

A new system of adult social care for England must find a solution that meets the needs of all people with dementia and carers as the largest group of people using social care services and the largest contributors to charges for care services. The Dementia Tax report makes two sets of recommendations. One set is for the development of a new system of funding and charging for care. A second set of recommendations is for the short term while a new system is being developed.

4i. Recommendations for a new national settlement

- **Scrap the dementia tax**. Move to a system where risk is shared beyond people with a specific medical condition like dementia.
- **A new system must deliver good quality care at a fair price.** The quality of care must be improved if people are to buy into making a contribution.
- **Scrap the current fair access to care system** which means no one with lower level or moderate needs gets help. Deliver a new national resource allocation system.
- **End age discrimination in funding of care** which sees much more generous packages of care for children and younger adults with disabilities than for older people with dementia.
- **Recognise the role that carers play** and make sure that they are not financially disadvantaged by caring.

4ii. Recommendations for the short term

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- Early implementation of the National Dementia Strategy for England. This will start to make a real difference to quality of life for people with dementia and is a necessary pre-requisite for a sensible debate on who pays for care. Effective implementation will require significant investment.

- Full steam ahead on the implementation of personal budgets. People with dementia and their carers must be given the support they need to make effective choices.
- Short term funding to prevent social care collapse. The government needs to consider how to improve funding allocations to local authorities so that people with lower level needs can get help
- Short-term measures to reduce financial pressure on families need to be considered. Specifically, thought should be given to:
  a. Raising the rate of attendance allowance
  b. Scrapping the age threshold for disability living allowance (currently set at 65 years of age)
  c. Raising the personal expenses allowance for people in care homes
  d. Raising the income and capital thresholds which determine who has to pay for care
- **An ambitious programme of research.** In line with the recommendation in the draft National Dementia Strategy for England, an ambitious plan for dementia research must be developed to prevent or delay the onset of dementia and to reduce the costs of dementia care

Response to the specific consultation questions
1. What more do we need to do to make our vision of independence, choice and control a reality?

People with dementia currently form a large proportion of those who need help and support to live independently. This number will increase substantially as the population ages over the next 10-15 years. The cost will rise substantially even IF we were to do nothing to improve help and support available for people with dementia and their families. It is therefore the case that without improving care and support for people living with dementia in a way that promotes empowerment and choice, the personalisation agenda will not deliver the type of change envisaged by the Department. There are three significant steps that need to be in place for the vision of independence, choice and control to become a reality:

a. Improve early intervention in dementia.
The National Dementia Strategy proposes a significant shift in the development of dementia services to ensure that people with dementia are diagnosed and treated earlier to put them in control of their lives. All elements of the Dementia Strategy are intended to support earlier intervention. However, the elements of the Dementia Strategy which will particularly help to create the shift to independence, choice and control are:

- Improving public awareness about dementia.
- Early diagnosis of dementia through the development of memory services.
- Access to national and local information about dementia and services, facilitated by a local named contact.
- Access to peer support networks to help people with dementia and their carers to support each other with practical advice and a listening ear.
- Workforce development to improve the understanding of all health and social care staff.

b. Improve supply of dementia community services
The issue on dementia is not demand for services, but supply. The range of options available for people with dementia and their families is often limited, particularly in the early stages of dementia. It is not simply that there are not enough services to go round. It is also that the range of services available do not support an effective range of choices for people. The development of personal budgets will start to stimulate the market for dementia services, however, there is much that can be done using the Dementia Strategy as a framework for development to ensure that a range of services exist for people to draw upon. Good examples would be the development of dementia home care services, information channels and peer support networks.

c. Develop clearer evidence, information and support about how personalisation can work for people with dementia and their families
Limited information is currently available about personalisation in dementia and how personal budgets can work for people with dementia and their families. The recent SCIE work showed that making choice and control attractive to older people in general and people with dementia in particular requires work. Therefore in the next 3-5 years priority needs to be attached to understanding personalisation in the context of dementia. The Society will be focussing energy on this area of work. We have applied through the DH TSIP programme for funding for a research project over 2 years to develop improved evidence about how personalisation can work for people with dementia with this end in mind.

2. What should the balance of responsibility be between the family, the individual and the Government?

The majority of care for people in the early and moderate stages of dementia is provided by people with dementia and their families. In addition people with dementia and their families pay significant sums towards the costs of their care. The current system of charging for care hits people with dementia harder than other groups for the reasons described in the Dementia Tax report:

- Dementia care, when it isn't provided by families, is usually provided by social services departments, compared to other conditions like cancer where the majority of care is provided free by the NHS. This dementia care is means tested so people with dementia end up paying significant amounts of money.
- Dementia can last many years meaning significant bills for care.
- The end stages of dementia care often require long term care which is means tested, meaning bills for thousands of pounds. Nursing care which is dominated by people with dementia is particularly expensive.

When Alzheimer's Society has talked to people with dementia and their carers in consultation about the proposed Green Paper on a new care and support system, people accept that it is reasonable for families to provide care and support and also for people to make a contribution towards the costs of care. However, they also believe that the state has a responsibility to make a significant tax-funded contribution towards the costs of dementia and for the balance of contributions to be clear so that people understand what their responsibility is.

Alzheimer's Society takes the view it is insufficient for the state to pay for the provision of information and advice as the universal offer. That is simply what should be in place

already. In addition the state needs to provide a minimum level of care free to all. A proposal could be developed using the principles used by the Wanless model and (or in combination with) the solution proposed by the International Longevity Centre. Families are paying vast amounts towards the cost of care, the state must recognise its responsibility.

The Hampshire County Council Commission of Inquiry into the future services for adults in need of support and care recently proposed raising the capital disregard to £50,000. Alzheimer's Society does not support this proposal as it represents tinkering rather than the systematic reform that is required and does not help to create a transparent and sustainable system.

3. Should the system be the same for everybody or should we consider varying the ways we allocate funding according to certain principles?

a) Should there be one system for everyone or different systems depending on the type of need for care and support that someone has?

The current system of support and charging for care is heavily biased against older people in general and people with dementia specifically. Cost comparisons show that in 2006/07 local authorities were spending an average of £759 per week on care for children in foster care or children's homes, with the cost rising to an average of £2,402 per week for care in a children's home. For adults with learning disabilities the average is £971 per week. This compares to an average of just £444 paid for residential care of older people and £451 paid for care of older people in nursing homes. 1 Anecdotally it is not unusual to hear of local authorities paying £1,500 per week for residential care for people with a learning disability while being willing to pay only £350 per week for dementia care.

Any new system must be age inclusive and ensure that older people can receive the same levels of support as younger people, appropriate to their needs. One of the priority areas for a new system of care and support must be creating a system that is transparent and simple to understand. Creating differential responses according to types of need for care and support will seriously jeopardise that intention and should be resisted. Although it may appear tempting to provide increased support to end charging just for care in people's own homes, this would also be a mistake. Significant numbers of people with dementia will continue to need long term care until treatments are found which change the disease process. Increased carer support and a range of community services need to be in place to help people remain in their homes for as long as possible. For people with dementia these services do not currently exist to make staying at home a real choice.

b.) Which is more important to us: local flexibility or national consistency?

The Society cannot see the benefits of local flexibility in an area, which is plagued by inconsistency, anger, and the need to create a sustainable solution. There is an overwhelming view from people with dementia and their carers that in order to create a system that is sustainable, transparent and fair it is crucial that there is national consistency in the rules being applied in relation to eligibility, access and charging. Service delivery is always going to vary locally dependent on choices and local context. However, the rules that govern assessment of need, eligibility for support, access to

care and charging should be consistent across England. It should not be the case that someone with 'low level' needs can access help in one place but not in another.

c.)What should the balance be between targeting government resources at those who are least able to pay and having a system that supports those who plan and save?

No system which seeks to provide an effective safety net for people without significant means, but which falls short of free care for all, will ever overcome the charge that it creates disincentives to saving. However, there are a number of false assumptions about charging for care that need correcting and a number of solutions which can deliver a partnership approach.

There is a mistaken view that charging for care only affects people who have significant amounts of savings. This is untrue. People in care homes contribute significant amounts towards the costs of care in contributions through state pension and occupational pensions payments. In addition many families are now paying to top up the costs of care.

The state is rightly encouraging people to make provision for later life through saving. However, for many people who have seen the experience of others paying for care, or in couples where there has been joint saving to plan for care, the current costs of care present a significant disincentive to save. The current system is perceived to penalise people who have saved modest amounts for retirement. A sustainable system which maintains public support will have to provide a minimum level of care free for all and then offer partnership funding to deliver the rest.

In discussions about the Wanless partnership model people with dementia and carers are attracted to the simplicity of the system. What people are more unsure about is talk of a 'minimum guaranteed offer'. Attractive as this concept is, people are suspicious to sign up to a system unless there is absolute clarity on what 'the minimum' is. Alzheimer's Society takes the view that moving beyond debate on the principles of a new system cannot happen effectively until there is a proposal on the table. When the Green Paper is available we look forward to engaging people with dementia and their carers in discussion about whether it will deliver.

Getting the right system of quality support in place is as important as delivering a fair system on charging for care. If the Green Paper only tackles the 'who pays?' question but fails to explain how we will deliver a more ambitious partnership funding framework for care, it will have failed.

A hard copy of this letter and a full version of the Dementia Tax report will be sent by post to the care and support team. If you have any questions about the report or would like to meet to discuss our work in depth, please do contact us.

Yours sincerely
Louise Lakey
Senior Policy Officer

Department of Health - London

This document has been written and submitted by Ian Winter, Deputy Regional Director, Social Care and Partnerships, Department of Health in the London Region.

1 (a) what difficulties do older Londoners face in accessing home care services that meet their needs?

The Department of health policy team for older people and their carers seek to promote social inclusion and enable individuals control over their lives, ensuring respect and choice.

This enables older people to live independently for as long as possible, to benefit from tailored care and support, and experience an enhanced quality of life.

Social care services usually, are only able to offer help to those with substantial or critical needs, measured by the fair access to care policy (FACS). Social care must follow statutory guidance as set out in (FACS) Policy Guidance[8]. FACS sets out an Eligibility Framework for all adult social care services.
The Eligibility Framework is graded into four bands – critical, substantial, moderate and low, which describe the seriousness of the risk to independence or other consequences if the needs of the individual are not addressed.
Local Authorities do have some discretion when setting its eligibility criteria, taking into account its available resources, to decide which bands of need will be met. Most Local Authorities decide it can only fund services to meet needs where the risk to independence consequences fall into the critical or substantial band.

The national survey report on home care for older people[9] clearly describes experiences of older people who use services; however, the report also highlighted that:

- Some older people find that they are assessed for care but because they do not meet the fair access to care eligibility criteria they are not able to receive care:
- Some individuals are offered care that they may not want and there is a lack of choice.
- Some staff appear not to be suitability trained, i.e. no specialist training or skills in the care of people with dementia to help them working with this client group
- There appears to be lack of staff continuity which prevents a professional relationship developing between client and carer and erratic staff attendance (e.g. arriving late) which may make clients feel vulnerable.
- Self-funders may not know what services exist or how to access them.

(b) How could these difficulties be tackled?
Apart from informal family members or friends, who provide the vast bulk of care and Support; homecare is probably the single most important service involved in supporting

[8] Department of Health 2002 FACs policy guidance
[9] SPRU research: Making home care for older people more flexible and person-centered (2005)

people with dementia in their own homes, for example;
The way that home care is commissioned, and the quality of services, is of critical importance. World Class Commissioning illustrates the principles of better health, better care and better value and underpins contractual activity to ensure that services *add life to years and years to life*'.

The shift towards personalisation will lead to major changes for commissioners. responsibility will shift from traditionally focusing primarily on the needs of those who receive publicly funded services, to considering the well-being and needs of the whole community and ensuring that care for people gives them choice and control.

The Department of Health is committed to improving the home based social care to individuals and has already instigated the overarching aim of self directed support, which is at the heart of the personalisation agenda, enabling people who need support to make real choices. This positive way of working involves a power shift and a move away from conventional services or support where agencies and professionals retain control in a situation to where people have control over their own lives, regardless of their need for support. Moving from *doing to* - to working *with* people. Using this philosophy individuals are empowered to choose for themselves the nature and level of support they access with choices from a wide range of networks, options and opportunities.

Key elements of a personalised adult social care system were highlighted within the Department of Health's strategy document Putting People First[10]. This approach will ensure that people, irrespective of illness or disability are supported to:

- Live independently
- Stay healthy and recover more quickly from illness
- Exercise maximum control over their own life and where appropriate the lives of their family members
- Sustain a family unit which avoids children being required to take on inappropriate caring roles
- Participate as active and equal citizens, both economically and socially
- Have the best possible quality of life, irrespective of illness or disability
- Retain maximum dignity and respect

Putting People First[11] also requires the development of System-wide transformation that is developed and owned by local partners, covering objectives such as:

- Incorporating the findings from the local Joint strategic needs assessment
- Commissioning which stimulates quality provision offering high standards of care, dignity and maximum choice and control.

10
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

11
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH...

- Use of community resources (especially the voluntary sector) so that prevention, early intervention and enablement becomes the norm.
- Supporting people to remain in their usual place of residence for as long as possible.
- Universal information, advice and advocacy services for people needing services and their carers irrespective of their eligibility for public funding.
- Person centered planning and self-directed support to become mainstream and underpin individually tailored support packages.
- Personal budgets for everyone eligible for publicly funded adult social care other than in circumstances where people require emergency access to care.
- Direct payments, utilized by increasing numbers of people, as defined by locally set targets in Local Area Agreement's[12].
- Family carers to be treated as experts and care partners and should be supported to further develop their skills and confidence[13].
- Systems which act on and minimize the risk of abuse and neglect of vulnerable adults[14]. For example the Department of health has led the planning and formation of local workforce development strategies that are focused on raising skill levels and providing career development opportunities across all sectors.

However it is very important to remember that older people themselves are key to achieving transformational service development: they are a majority group of stakeholders and must be part of future planning, thinking, design and developing a health and social care system fit for the future.

The Department of Health's policy relating to older people's services and initiatives is responding to the needs of an ageing society and has been moving towards empowering individuals to have an increased voice with more choice and control.

The key strands of the Department of Health policy are outlined in the following publications

- Opportunity Age, the existing strategy on ageing

Soon to be refreshed through building a society for all ages

- The Independent Living Strategy
- The National Dementia Strategy
- Lifetime Homes, Lifetime Neighborhoods
- Sure Start to Later Life
- Our health, our care, our say
- Putting People First and more recently

12Carers strategyhttp://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006522
http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Localareaagreements/index.htm

13 Carers strategyhttp://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006522

14http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4003726

- The Green paper, shaping the future of care together, currently out for public consultation until the 13th November 2009[15]
- The prevention package for older people[9]

3 (a) what challenges are London's service providers and funders facing in providing home care services for older people?

London faces a number of challenges in providing home care services for older people including:

- The Diverse nature of the population, for example London has a high proportion of black and minority ethnic communities
- An ageing population that is growing
- Areas of high deprivation
- High cost of living
- Difficulties in recruitment due to poor salary levels
- High turnovers of staff because of transient workforce

(b) How can these challenges be met?

Working with commissioners of local services to agree service specifications, outcomes and funding. The vision for world class commissioning[16] outlines what it means to be world class commissioners and how world class commissioning will impact on population, health and well-being. It is a shared vision, which has been developed jointly by the department of health and wider health and community care.

A positive example of working in partnership[17];
Oasis, in Southwark, a community-based partnership in which the support staff work closely with South London and Maudsley NHS Trust, community mental health teams and mental health older adults teams. Its innovative approach is said to have had dramatic results in the borough ensuring that people can remain living at home for longer and with increased well-being. Staff assists those with memory loss to re-learn everyday skills and support people to get out-and-about in their communities. Assistive technology is used to monitor people's activity overnight and when they are on their own, picking up developing problems much earlier and dealing with them before they become more serious. The local authority strategy group has assessed this service as the best one provided in the borough and the evaluation appears to prove that it is cost effective in enabling early discharges and preventing hospital admissions by timely intervention.

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15 hhttp://www.dh.gov.uk/en/News/DH_106903
9 Carers strategyhttp://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103146
16 http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/Vision/index.htm
17 http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPProduct/DOH_NDS_commissioning_home_care.pdf page 11

The personalisation agenda may also address some of the challenges. The Department of Health's personalisation approach requires services to consider and respond to the individual's needs and preferences rather than expecting them fit in with current service provision. The Department of Health announced that from 2009 there will be pilots that build on experiences with individual budgets[18] in social care, to test personal health budgets as a way of giving people greater control over the services they use. Several London boroughs are part of the pilots[19]

Individual Budgets[20] are central to the aim of modernising social care in England. They build on the experiences of direct payments and are intended to offer new opportunities for personalised social care. The idea behind individual budgets is to enable people needing social care and associated services to design that support and to give them the power to decide the nature of the services they need. Key features are:

- A transparent allocation of resources, giving individuals a clear cash or notional sum for them to use on their care or support package
- A streamlined assessment process across agencies, meaning less time spent giving information
- Bringing together a variety of streams of support and/or funding, from more than one agency.
- Giving individuals the ability to use the budget in a way that best suits their own particular requirements
- Support from a broker or advocate, family or friends, as the individual desires.

One of the key findings from the Individual Budgets Evaluation Network (IBSEN).[21] Was following the evaluation of the individual budgets pilots, the report detailed that older people benefited slightly less than other groups, in particular in relation to the demands of finding and managing their care.
However there is a real confidence among health, social care and the voluntary sector that with further development and support individual budgets will be an effective model for older people; particularly by providing support and advocacy which will encourage individuals to get more actively involved in planning and arranging care.

The key areas identified in the individual budgets guidance that need to be addressed in order to make services more personalised for Older People are:

- Improving access to information and assessment - the *front door for services*
- Adopting person centered approaches and support planning with older people
- Providing different ways for older people to have and manage their money to purchase the care they need
- Developing a flexible and diverse market to ensure that older people get personalised services

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[18] http://www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH_090018

[19] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_099158.pdf

[20] http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Individualbudgets/DH_4125774

[21] http://php.york.ac.uk/inst/spru/research/summs/ibsen.php

The London Joint Improvement Partnership (JIP) Efficiency Programme is working to support London Boroughs in achieving the target of 3% cashable efficiency savings per annum in Adult Social Care, as required through CSR 07. This is a challenging target and the projects selected to meet this challenge also deliver on the prevention & early intervention agenda; while underpinning delivering transformation efficiently as set out in Putting People First.

All 33 London boroughs have signed up to roll out the Retail Model for Simple Aids to Daily Living – a project which within two years will transform the way all Londoners gain access to simple aids, increasing accessibility and streamlining costs, generating £2.88M savings per annum from year 4 onwards making, these products universally available. Further priorities for London include Homecare Re-ablement & Assistive Technology. Both of these projects are providing resources in terms of tools & practical support based on good practice to enable boroughs to accelerate release of the benefits from effective implementation of these approaches, both of these projects offer significant benefits to the individual & carers while delivering cashable savings by reducing the dependency on residential care options.

These projects and service changes will directly benefit older people funding to support this through the Department of Health and Capital Ambition, who have made a grant of £2.1m over 09/10 - 10/11.

4. What impact do you think the proposals in the new Green Paper on long-term care could have on home care services for older Londoners?
The National Green Paper Team have been asked to respond.

6. How effective is joint working between home care services and other services such as NHS services for older people?
Lord Ara Warkes Darzi of Denham's report[22] highlighted the importance of partnership working across the whole system. The key elements local authority leadership accompanied by dependable partnership working with the local NHS, other statutory agencies, third and private sector providers, users and carers as well as the wider local community. The objective, to create a high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carers.

There are some examples of good practice in partnership working across London, for example

- Camden have well established joint commissioning arrangements in place.
- Kingston-upon Thames have integrated Health & Social care Community Mental Health Teams for Older people.
- The National dementia strategy[23] London demonstrator sites these are in;[24] Lambeth & Southwark, Croydon, Hackney, Newham, Kingston and Enfield.

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22 http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085825

23www.dh.gov.uk/.../Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm

- Counsel and care journey working with Westminster Social Care

In Britain we rightly aspire to a care and support system in which everyone's needs are met and people can live their lives to the full. The fact that as a nation we are now living longer is clearly a cause for celebration, but it also means that the pressures on our care and support system are greater than ever before. The Departments of Health's work will continue to enable people be responsible for their own health, developing prevention packages with more health promotion and education that are available to all.

Ian Winter
Deputy Regional Director, Social Care and Partnerships

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097629

Sub027

Harrow Council

Dear James

Thank you for the invitation to comment on the Investigation into homecare based social care for older Londoners being undertaken by the London Assembley's Health and Public Services Committee. Thank you for extending the deadline for us to comment.

I am responding from the Contracts team at Harrow Council with our views.

1. **What difficulties do older Londoners face in accessing homecare services that meet their needs? How could these difficulties be tackled?**

The key issues that are raised by the older users of homecare services in Harrow that we have picked up from our twice yearly independent Age Concern surveys of our principle provision is the desire for greater continuity of care (having the same carer or team of carers deliver care), more choice over the times that Carers attend, some would like more flexibility about how and when the services are offered.

The difficulties can in theory be tackled by delivering the personalization agenda in an innovative way that links outcome based support planning into flexible provision. However there are challenges to delivering this, which are detailed in the response to Q3.

2. **What good practice exists in providing homecare services that meet people's needs?**

There are a number of models that are being developed to offer increased choice and re-ablement through homecare provision including offering – service user individual budgets to purchase their own services; offering Individual Service Funds that apply to one provider but which offer increased choice – Harrow hope to pilot this approach in the next few months.

There are also IT solutions to brokering the market place – Slivers of Time and Shop 4 Support for example.

Harrow and West London colleagues are leading on developing some West London procurement projects to meet the needs of personalization across the sub region e.g. framework agreements.

3. **What challenges are London's service providers and funders facing in providing homecare services for older people how can these challenges be met ?**

The funders are facing challenges about the cost of offering homecare services with increasing demographic numbers requiring the services and less money to deliver. The management of the shift from block contracted arrangements to SDS at the same time as taking into account quality and safeguarding issues is a clear challenge to balance for funders as well as ongoing monitoring and where brokerage for the services sits.

The providers are facing challenges about developing personalized services and operating without the guarantee of a block contract income.

There is a common issue about developing a workforce that is appropriately skilled and flexible enough to deliver the needs of service users.

4. **The proposals in the new Green Paper - how will they affect homecare?**

It will be interesting to see if the availability of homecare will be affected by the proposed changes to funding including changes to attendance allowance as some people use this currently to fund care in the home.

5. **The Mayors role?**

The Mayor could champion the issues that need to be addressed with the social care and health economy in London.

6. **How effective is joint working between homecare services and other services such as the NHS services for Older People?**

Variable – but there has been effective working between community nurses and homecare providers in Harrow operationally as well as on the subject of developing policies e.g. for medication.

Yours sincerely

Nick Davies
SM SP Contracts and Brokerage

Sub028

Hillingdon Council

Dear James

Call for views and information:
Investigation into home based social care for older Londoners

Thank you for your letter of *6* August and I apologise for the delay in replying.

Providing comprehensive home based care services to meet the needs of older Londoners continues to be a major challenge and is fundamental to the success of the new agenda surrounding personalisation and self directed support.

Home based social care is critical in a number of areas. Evidence shows that effective early intervention and intensive support when older people first face difficulties ensures better outcomes and less reliance on costly ongoing services. There needs to be an increased focus upon home based social care services providing effective reablement. In Hillingdon our in-house home care service is focussed upon this approach to good effect, reducing reliance on more costly packages and leading to greater independence for older people.

The personalisation agenda will bring greater expectations from older people around quality and choice which means Councils across London will face the challenge of developing the market to ensure that new and alternative providers are available to meet these needs and expectations. You may be aware that Councils across West London have come together to establish a joint initiative around procurement and their first project is to ensure the procurement of domiciliary care services, which provide greater quality and choice as well better value for money.

As part of the self directed support agenda, the West London Authorities are also working closer together to develop and provide personal assistants to support people through the new agenda and provide the support older people need.

Future funding of all social care services is obviously the subject of a major debate following the publication of the Green Paper. The Green Paper's main focus is upon the future funding of long-term care primarily around the issue of paying for residential and nursing home care. It is my belief that the development of effective home based services needs to be central to the debate. Few older people really want to loose their independence and end their days in institutional care. The Mayor should encourage Councils to develop new and innovative solutions such as Extra Care Housing and the development of assistive technologies to ensure we can maximise people's independence.

In Hillingdon we have named our Transformation Programme as ***Support, Choice and Independence*** as this is what older people are telling us they want for the future.

We also look forward to greater integration between social care home based services and those provided by health services colleagues. Good working relationships exist on the ground but often structural and professional issues get in the way of effective and

efficient responses. There is often a blurring of roles between home care services and community nursing services and a radical re-examination in this area could provide much needed efficiencies and a better response to customer need.
I hope you find my comments helpful and if you would like any further information do not hesitate to contact me.

Yours sincerely

Cllr Philip Corthorne
West Ruislip Ward and
Cabinet Member for Social Services, Health and Housing