



BRIEFING

Dementia care in London

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Executive summary

Providing high-quality care and support for the increasing numbers of people with dementia is one of the most challenging and complex issues of our time. There are currently around 700,000 people in England with dementia, and dementia is thought to cost the UK economy somewhere between £15 and £23 billion a year (Alzheimer's Society 2009), considerably more than other major health conditions like cancer and heart disease. These costs are spread across health and social care services, as well as individual costs borne by people with dementia and their carers through loss of earnings and payment for personal support. The number of people with dementia is set to double to 1.4 million in the next 30 years and the costs are expected to treble (Goodchild 2009). The size of the challenge for health and social care commissioners is considerable.

ippr's work in this area responds to the need for service providers and commissioners to have a better evidence base on ageing in London.¹ This briefing identifies areas of unmet need, highlights problems with current provision, and draws attention to models of best practice. Key findings from the report are summarised below.

GPs in the capital that are able to diagnose dementia and provide sufficient advice and signposting are the exception, rather than the rule. Just 31 per cent of the capital's GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia (CSL 2009). A lack of early diagnosis results in poor-quality care and places a burden on acute services further down the line.

Recommendations:

- Training on dementia needs to be embedded early in medical training.
- Voluntary and community groups should offer ongoing training packages to GPs, to provide an insight into local needs and services.
- GPs should issue 'information prescriptions' to ensure people are channelled towards the relevant advice.

Services for people with dementia often fall between the health system and care provided by local authorities. People with dementia can lose out as a result of this divide. The government's reforms to health and care, especially the introduction of Health and Wellbeing Boards, have the potential to narrow this divide. But there is a danger that health and social care commissioners will not be held properly accountable for working in partnership. Systems need to be put in place to strengthen the links between health and social care and to support joint working. Safety nets will need to be put in place to ensure that people with dementia do not lose out.

Recommendations for integrating health and social care services:

- Embedding advice services in surgeries will help GPs to signpost patients towards services provided by local authorities and the third sector. This would provide a much needed link between health and care services.
- The new Health and Wellbeing Boards should include dementia as a priority in their local Joint Health and Wellbeing Strategies. Community organisations supporting people with dementia should engage with the Health and Wellbeing Boards to make sure dementia is made a priority locally.
- Co-location of health and social care in the same buildings has been achieved in some parts of the country. This needs to be rolled out further to ensure greater information sharing and close working between practitioners.

1 See <http://www.ippr.org/research/themes/project.asp?id=4210>

Recommendations for social care commissioners:

- We urge local authorities to retain the role of the health overview and scrutiny committees to ensure that decisions made by commissioners are properly scrutinised.
- Personal budgets are important for holding commissioners and service providers to account. Dementia patients and their carers should be encouraged and supported by local authorities to hold their own personal budgets to pay for services that will improve their own individual wellbeing. But for people with dementia, personal budgets need to be reviewed on a case-by-case basis and monitored closely for suitability as the condition progresses.

Recommendations for health care commissioners:

- The NHS Commissioning Board should ensure that the quality of dementia care is included in the new outcomes framework by which GP consortia will be held to account.
- One of the new 'pathfinder' GP consortia should pilot an early-intervention approach to dementia care. This could provide the necessary evidence base to reassure future consortia that commissioning dementia services is a worthwhile investment, which can result in savings further down the line.

Some community and voluntary organisations are struggling to receive commissioned funding and many organisations find partnership working and forming consortia extremely challenging. Proposed changes to health and social care will result in increased reliance on voluntary and community services, particularly through commissioning services. But identifying good-quality community provision can be difficult. Efforts to support community-based activities will have important long-term financial savings, in particular preventing unnecessary hospital stays. Commissioning Support for London has noted that older people with dementia occupy 20 per cent of acute hospital beds across England, when in fact around 70 per cent of these may be medically fit to be discharged (CSL 2009).

Recommendations:

- An audit of services provided for people with dementia, or an approved list of providers, could help service commissioners (and patients holding personal budgets) to identify good-quality services in the community.
- Local authorities should provide support for community organisations that want to collaborate to bid for contracts, especially as Commissioning Support for London will cease to fill this role in the near future.
- Voluntary and community organisations should recognise the opportunity presented by the increased reliance on their services, and rise to this challenge by filling service gaps in the following areas: training for commissioners, information, advocacy, end-of-life planning, support for carers, bespoke services for minority ethnic groups, and a more diverse range of social activities, especially for men.

Service provision for people aged over 80 with dementia is weak compared to services for people with early onset dementia and services for older people with physical health conditions. Stigmas of old age and of mental health persist – the combination of the two repeatedly results in poor quality of care in later life. Efforts to combat stigma and discrimination will be crucial as the number of people with dementia continue to increase.

Recommendations:

- Greater, widespread public awareness about dementia will go some way towards normalising and accepting dementia within society. Awareness-raising campaigns that project a positive approach to dementia (both nationally and locally), intergenerational activities in schools and community groups, community training (with retailers, the transport sector, landlords and so on) and community information-sharing schemes could help to raise greater awareness and prevent stigma.
- Community support and care is important but specialist care, particularly in the later stages of the illness, remains paramount. Voluntary and community organisations are well placed to offer training packages on dementia. These are particularly needed in institutional care settings and in palliative care services.

Service provision for older black and minority ethnic (BME) Londoners with dementia is struggling to meet current needs. Moreover, the number of over-80s in London from a BME background is projected to almost triple between 2010 and 2031, rising from 28,600 to 80,000. Over the same period, the number of white over-80s in the capital is expected to increase by 21,600 – a rise of just one-third (GLA 2009).

Recommendations:

- Commissioners should actively encourage user participation in the delivery of services. If BME groups are involved in the design and delivery of services, then such services are likely to be more culturally relevant.
- Commissioners will need to recognise the ongoing value and importance of outreach work and specialist services which do not always have easily definable outcomes.
- Services should be provided by communities themselves rather than ‘parachuting in’ outside providers. This will ensure information and services are provided in a more culturally relevant format for hard-to-reach groups.
- Health professionals need specialist, ongoing training in the support and care needs of people from BME groups.

About the Older Londoners Project

Older Londoners is a year-long programme of research by ippr, generously supported by the City of London’s City Bridge Trust. The project aims to provide commissioners and service providers with a better evidence base on ageing in London, and will identify ways to improve care and services for older people across the capital.

For more, see <http://www.ippr.org.uk/research/themes/project.asp?id=4210>

This is the first of three papers to be published on dementia care, social isolation and home-based care for people aged over 80 living in London. A website will also be launched that brings together data and projections on ageing in London in an interactive format.

1. Introduction and policy context

This paper focuses on the provision of care for older people with dementia² living in London. Given that the risk of getting dementia increases significantly after the age of 80, the fact that people are living longer means providing support for people with dementia will be a major challenge in the coming years. The number of Londoners aged over 80 is projected to increase by 40 per cent over the next 30 years, rising to 352,000 by 2031 (GLA 2009).

This challenge comes at a time of considerable change in health and social care policy in the UK. The way the NHS, GPs and local authorities commission services is set for major reform, and the community and voluntary sector is being encouraged to play a greater role in delivering services. Meanwhile, the way social care is funded remains uncertain, as policymakers await the findings of the Dilnot Commission on Funding of Care and Support.³

London faces a series of unique challenges in adequately supporting an ageing population. Poor mental health is more prevalent in the capital, compared with the national average, and there are a range of other factors – such as deprivation, the needs of diverse minority ethnic groups and social isolation – that can complicate service provision. The concentration of many local authorities in a relatively small area also makes commissioning and planning more complex, as people can easily move to neighbouring authorities to draw on different services.

This paper explores the challenges dementia poses to policymakers and service providers across London. It identifies areas of unmet need, highlights problems with current provision and draws attention to models of best practice. The remainder of this section explains the research methods and policy context for the study. Section 2 explores the scale and nature of the challenge that dementia brings to London. In Sections 3 to 6, the paper focuses on findings in four key areas: health and social care services, advocacy and advice services, support for social activities and interaction in the community, and providing services and support for a diverse community. The paper ends with conclusions and policy recommendations.

Methodology

ippr conducted primary research with 50 service providers, carers and service users across different boroughs in London.⁴ This paper also includes analysis of secondary data (including surveys and reports, academic literature and case studies of good practice) in order to build up a broader picture of the services available throughout London. Our research focused primarily on older people living in the community, rather than in residential care settings, in London.

UK political and policy context

All political parties are considering how public services can be effectively and efficiently delivered in a time of budget cuts. During Labour's time in office changes were made to promote greater choice and individual control over health services, notably through the personalisation agenda and control over personal budgets. Changes in funding and a commissioning model for care services have also had a big impact on the provision of health and social care in the public and voluntary sector. More recently, the Coalition government has set out its vision for cutting back the role of the state in order to hand more control and responsibility to the private and voluntary sector, as well as to individuals and communities.

Changes to health and social care services

There are many decisions that need to be taken about how the country handles the challenges faced by an ageing population, notably how health and social care are co-ordinated, managed and financed.⁵ The needs of people with mental health problems, and those of older people, are rarely either just 'medical' or 'social'. One local study conducted by the Nuffield Trust demonstrated that around 90 per cent of people who received social care also received secondary health care

2 The Alzheimer's Society defines 'dementia' as a term used to describe various different brain disorders that have in common a loss of brain function that is usually progressive and eventually severe. There are many types of dementia. The most common are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

3 Recommendations and advice from the Commission will be provided to the government in July 2011.

4 During the course of this project, 50 semi-structured interviews were carried out with service providers, carers and service users from a range of London boroughs. All interviewees gave their consent to take part in the research. Service user interviews took place with their service provider present.

5 The Health and Social Care Bill was introduced into Parliament on 19 January 2011. The bill is part of the government's vision to modernise the NHS to be built around patients and led by health professionals.

(CQC 2009). Integration of health and social care has been recognised as a key policy goal, but despite this, the challenge has been to turn policy aspirations into practice (Ham 2009).

The Coalition has embarked on a major shake-up of the NHS, which will replace the current system of control by the Department of Health and strategic health authorities (SHAs) and instead shift power to professionals, patients and carers. The Department of Health has indicated that its role will be 'more enabling and less directive' (Department of Health 2009). GP consortia will commission most NHS services, supported by and accountable to a new independent NHS Commissioning Board. Social care and public health will be provided and commissioned by local councils. The Department of Health has set out how GPs will play a critical role in influencing NHS expenditure, both through referral and prescribing decisions and (less directly) through the quality and accessibility of the services they provide for patients – and by extension through the impact these services have on emergency and urgent care provided elsewhere in the system (Department of Health 2010a).

Government responses to the challenge dementia brings to the UK

Both the previous Labour and present Coalition governments have acknowledged and acted upon the serious challenge that dementia brings to the country. In February 2009, the Labour government produced a five-year National Dementia Strategy, which has been influential in raising awareness about the scale and nature of the response required (see Department of Health 2009). The strategy identified three key themes: early identification and diagnosis, better treatment in both primary and secondary care, and good-quality information. The strategy was designed to tackle problems in existing services, such as the failure to diagnose dementia, services intervening too late, an under-skilled workforce, and a lack of integration between health and social care. It is undoubtedly an important driver in changing the way dementia care is going to be provided throughout the country in the future. The strategy also provides a positive discourse that moves away from talking about 'dying of dementia' and instead talks about 'living well with dementia'. It has a focus on targeting stigma and preventing misunderstandings about mental health and older age.

The strategy has been endorsed and supported by the Coalition government, which has also indicated that research into dementia would be a priority. The Department of Health has stressed that raising the quality of care for people with dementia, and their carers, is a major priority for the Coalition government.

Despite these developments, it appears that the dementia strategy is not always being well implemented in practice. The National Audit Office (NAO) issued a report in January 2010 warning that the strategy was at risk of failing to deliver on the Department of Health's 'ambitious and comprehensive' plans (NAO 2010). The NAO noted in particular that the Department of Health's failure to make dementia a national priority target for the NHS meant primary care trusts did not see it as a 'must do' area. It found a lack of local leadership and ongoing shortfalls in training, and said the Department of Health had underestimated the strategy's costs (Pitt 2010). The NAO report also highlighted that services were not being provided consistently well across London.

In March 2010, the All Party Parliamentary Group (APPG) on Dementia produced a report in response to an inquiry into the funding of the National Dementia Strategy. They found that two-thirds of Primary Care Trusts (PCTs) could not account for dementia strategy money. Just 70 of the 152 PCTs in England responded to the group's freedom of information requests, which the report said highlighted an apparent inability to provide information (Quince 2010). An inquiry into how to save money in dementia care and deliver better outcomes for people with dementia has been launched by Baroness Greengross, chair of the APPG on dementia, which will report by summer 2011. The inquiry is calling for evidence on ways to improve dementia care in a difficult fiscal climate for public services.

London policy context

As a cosmopolitan city with a diverse range of service users from different ethnic and socio-economic backgrounds, London needs to provide far-reaching and wide-ranging services for people with dementia. Research has also shown that people in London are more negative about their neighbourhood, have lower levels of trust, and are the least likely to speak to their neighbours (Schmuecker 2008). Given that social isolation is a problem in London and service users have such diverse backgrounds, providers face huge challenges in reaching out to those most in need of support.

London has responded to the challenges that dementia brings in many ways. Commissioning Support for London (CSL) produced a Dementia Services Guide in October 2009 which assists London's healthcare, social care and third sector organisations to commission services to improve

health outcomes and to offer comprehensive support to people with dementia and their carers. Innovation also thrives in the capital. There are many examples of good practice, both community-led and borough-led, some of which are explored in this briefing. Identifying and sharing learning from community-led programmes is one of the aims of *Appreciating our Seniors*, the Mayor's action plan for older people, although it does not refer to dementia specifically.

In the current changing policy environment for health and social care, much attention is needed to ensure that the NHS, local authorities and community organisations are well equipped to continue to support people with dementia and their family and carers. Before exploring the research findings and policy context in more depth, Section 2 explores the scale and nature of the challenge London faces in providing dementia care and support.

2. The challenge for London

Dementia presents unique challenges for London. These need to be considered against the backdrop of economic uncertainty and an ageing population in the UK today.

Demographic trends in London

London's changing older-age profile

- Around a quarter of a million people in London are aged over 80.⁶ The number of Londoners aged over 80 is projected to increase by nearly 40 per cent over the next 30 years, rising to 352,000 by 2031 (GLA 2009a). The size of the over-90 population in the capital is growing particularly strongly and is expected to almost double over the same period, increasing to almost 100,000. See Map 1 (over).

Larger rise in ageing among London's ethnic minority populations⁷

- While the white over-80 population is expected to rise by just under a third (28.7 per cent) between 2011 and 2031, the size of the ethnic minority population who are over 80 is projected to almost triple over the same period, rising from 28,600 to 80,000.
- This means that by 2031 ethnic minorities are expected to make up around a quarter of the over-80 population in London, compared to just 12 per cent in 2011. See Map 2 (p9).
- There is considerable variation in projected population growth among different ethnic minorities over this period: the number of Black Africans over 80 is expected to rise by nearly 300 per cent, whereas the same figure for Black Caribbeans is 96 per cent. Particularly high growth rates are predicted among populations where there are currently relatively few over 80s, for example, among Pakistani, Bangladeshi and Chinese communities.
- The number of older people and the number of people with dementia will rise especially quickly in several minority ethnic groups as first generation migrants from the 1950s–70s age into the groups most at risk for dementia (Knapp et al 2007).

The narrowing longevity gap between men and women⁸

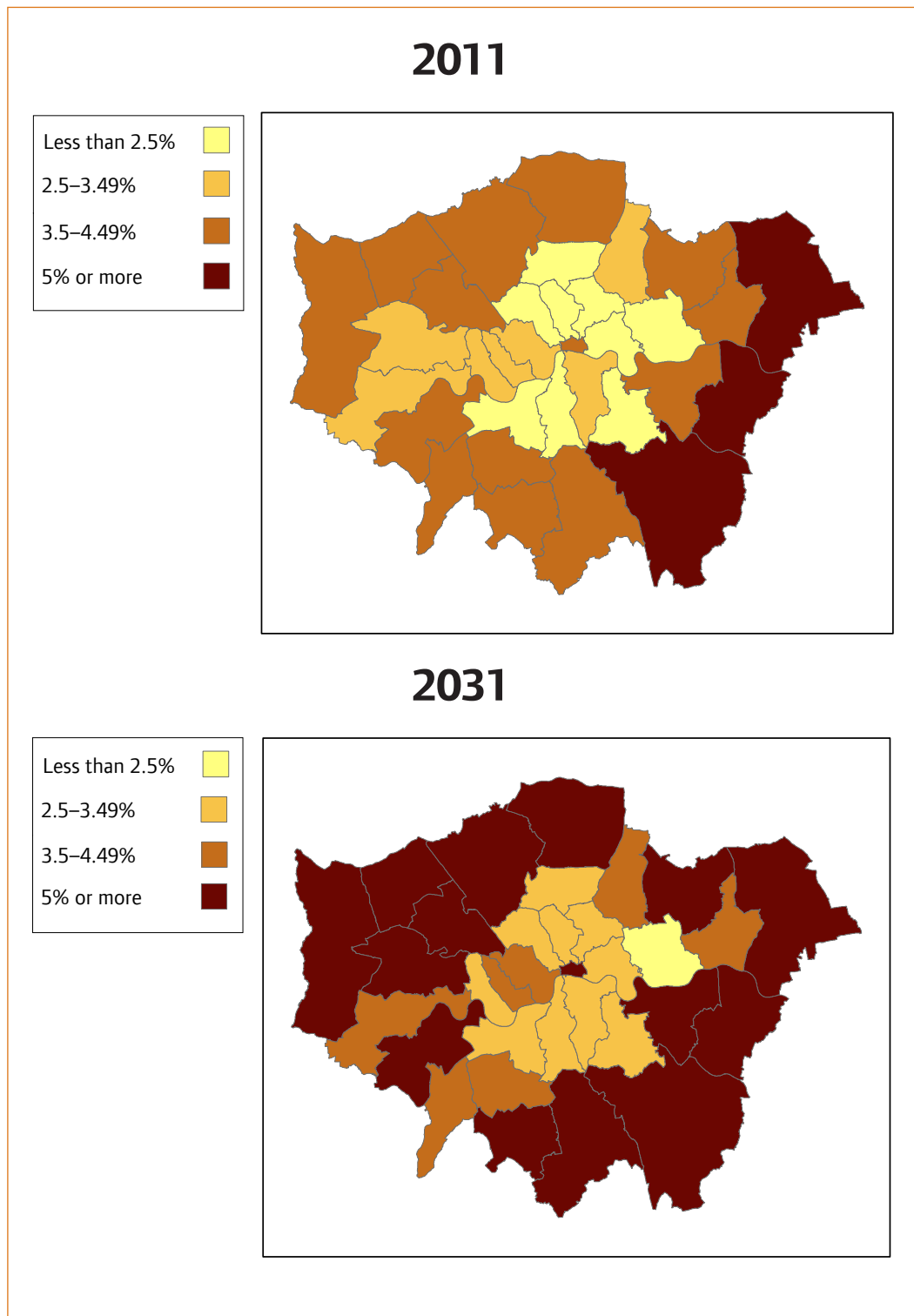
- There will continue to be more women than men over 80 years old – the female population is projected to be 207,800 in 2031, up from 160,400 in 2011, while these figures for males are 144,500 and 95,122 respectively.
- However, the gap in longevity between men and women is expected to narrow over the next 30 years: the number of men aged 80 and over living in the capital is projected to increase by more than 50 per cent, compared to an increase of less than a third among women.
- This has important implications for the number of single-person households headed by very elderly women, with potential knock-on effects for isolation and caring responsibilities among both men and women in this age group.
- It also means that, over time, men will make up a rising proportion of very elderly London residents, up from 37 per cent in 2011 to 41 per cent in 2031, which may have implications for the design and delivery of services.

6 See <http://www.london.gov.uk/older-people>

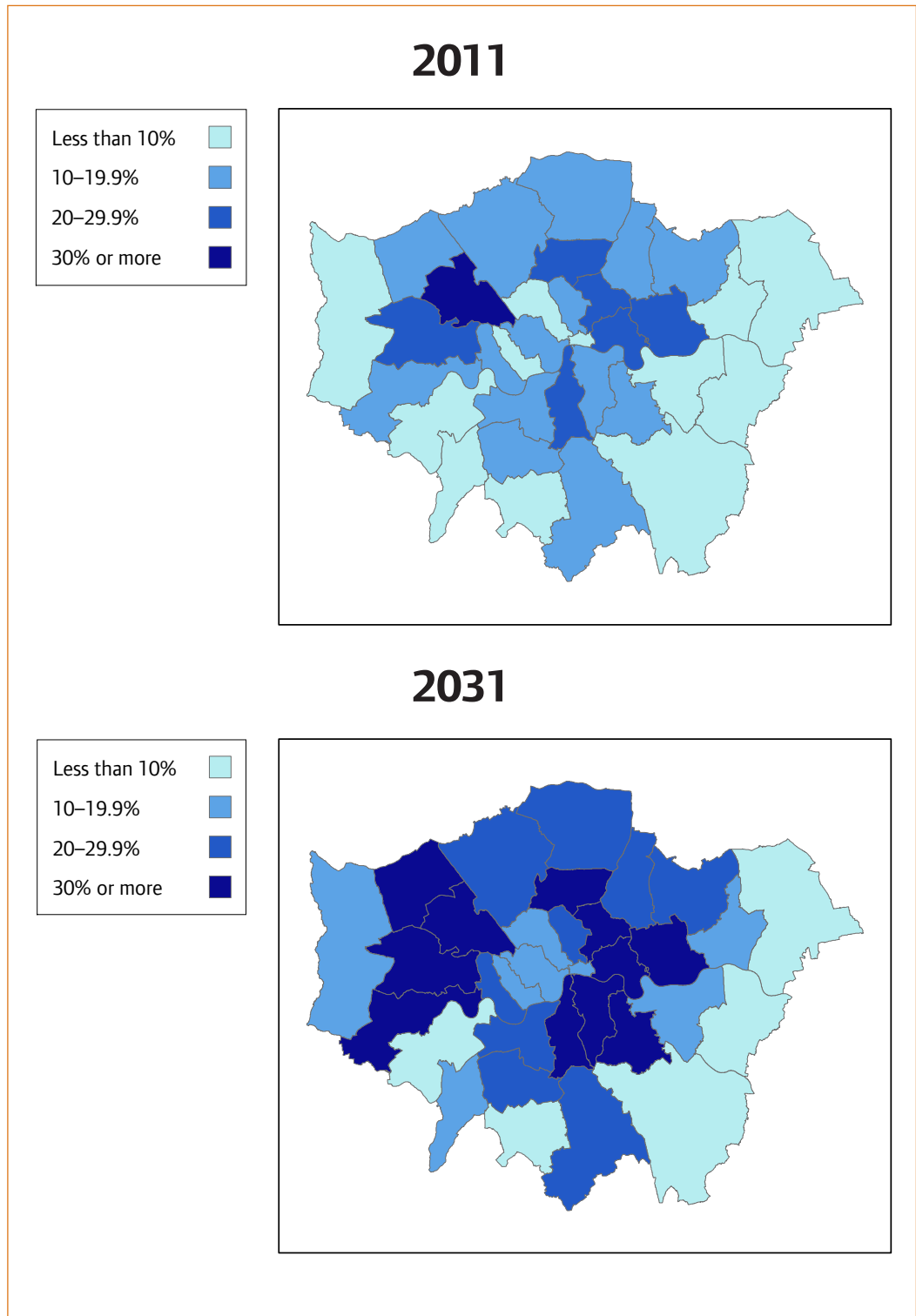
7 GLA 2009b unless noted

8 GLA 2009a

Map 1
80+ population as a
proportion of total
population



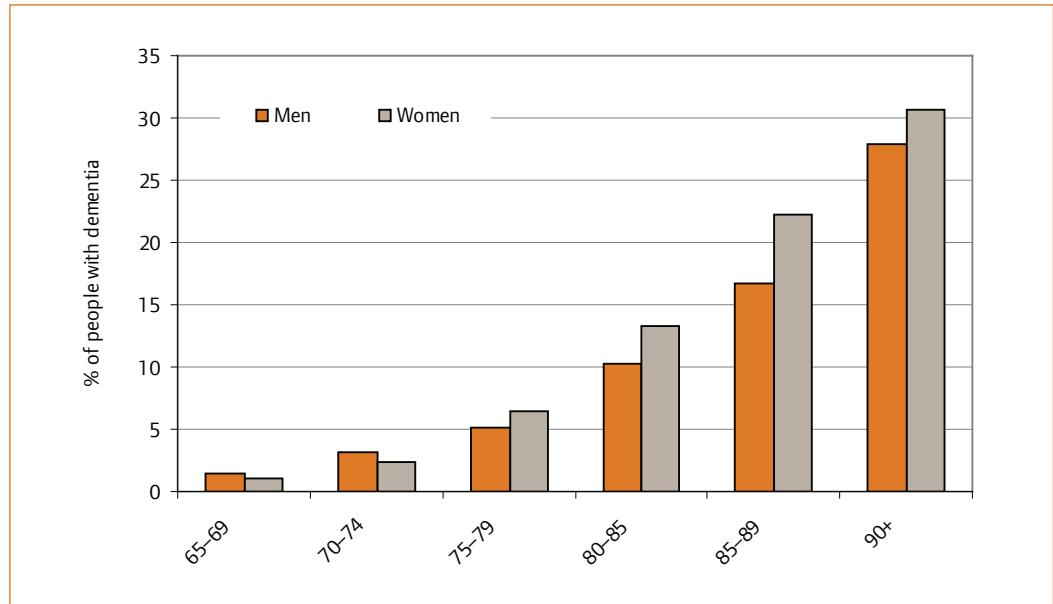
Map 2
BME population as
a proportion of 80+
population



Changing trends for dementia in London

- Recent estimates suggest that around 65,000 people over the age of 65 in London have dementia, including around 1,600 people with early-onset and 63,000 people with late-onset dementia (CSL 2009).
- The risk of dementia increases quite dramatically with age, as Figure 1 shows. In older age groups, the prevalence of dementia appears to be slightly higher among women.

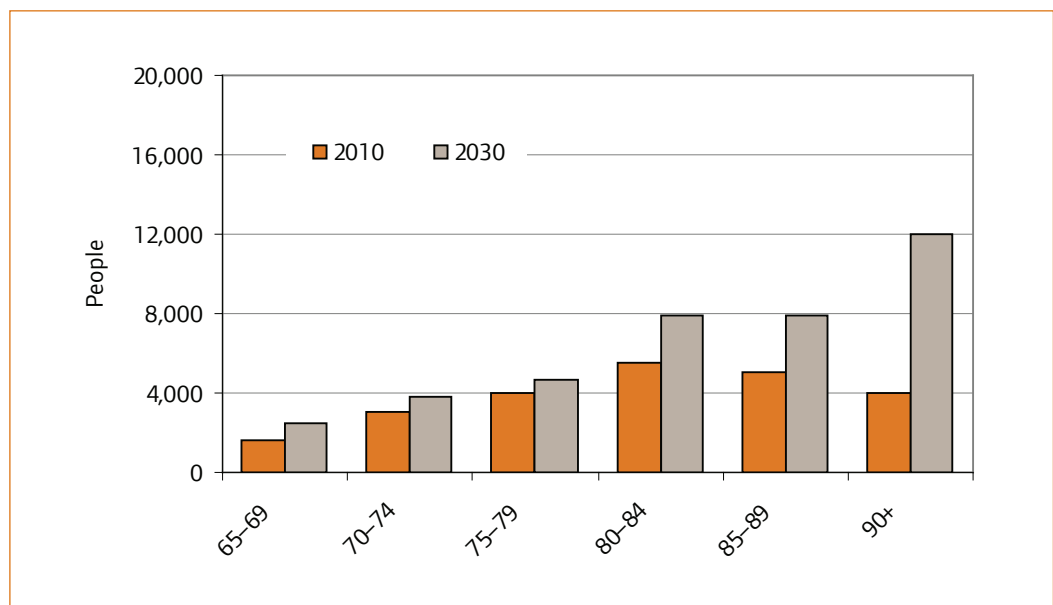
Figure 1
Risk of dementia for men and women by age group



Source: Knapp et al (2007)

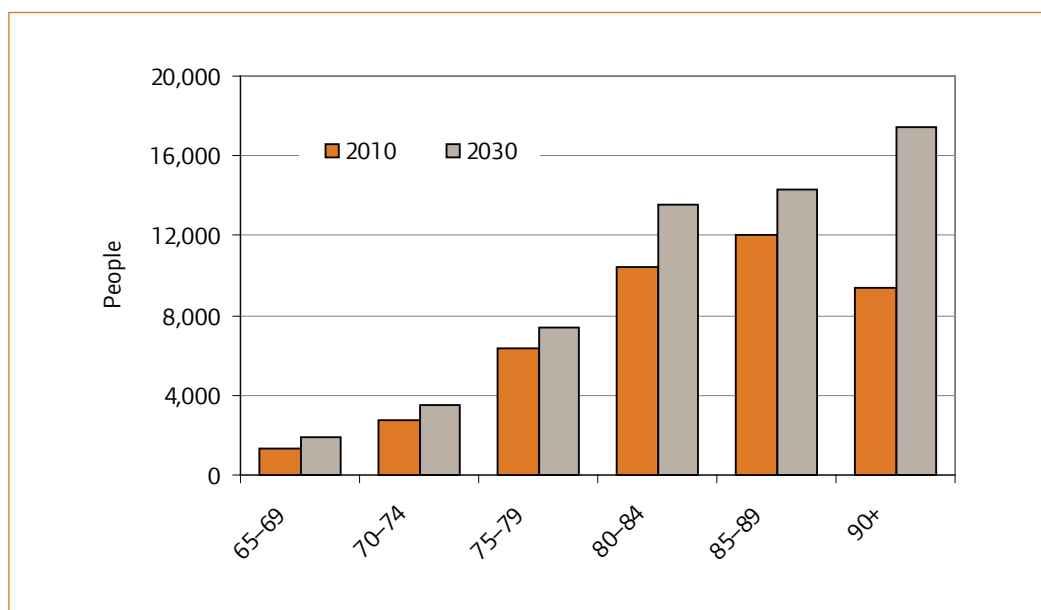
- Projections suggest that the number of people over 80 in London with dementia can be expected to rise by almost 50 per cent to 96,000 by 2030, as Figures 2 and 3 (over) show. A larger number of women will continue to have a dementia because they make up a larger proportion of older age groups, but there is no evidence that the risk of dementia by age or gender is set to change.

Figure 2
Trends in dementia by age group for men, 2010–30



Source: POPPI 2010

Figure 3
Trends in dementia
by age group for
women, 2010–30



Source: POPPI 2010

Spending on dementia in London

Table 1 outlines the spending on dementia for London, based on analysis in CSL’s Dementia Services Guide.

Table 1
Estimated public
sector annual cost
of services used
by people with
dementia aged
65 and over in
London (2009/10,
£ millions)

	Mild dementia (community)	Moderate dementia (community)	Severe dementia (community)	Dementia in care home setting	Total
NHS	70	39	16	39	163
Social service costs	138	100	46	11	295
Care home costs (social service funded)				386	386
Care home costs (NHS funded)				190	190
Total	208	139	62	626	1,035

Source: CSL 2009: Appendix 6

Note: The costs associated with ‘informal care’ and self-funded care home costs have been excluded.

It is widely accepted that preventative, joined-up approaches to health and social care should help improve efficiency, which in turn will achieve cost savings. Given the high costs associated with caring for patients in care home settings, investing in services that allow people to remain in the community could yield significant ‘downstream’ savings. CSL conclude that: ‘on a purely financial basis and just concentrating on the NHS component, the investment boils down to: investing “upstream” to yield savings “downstream” in two key areas: reduced use of care homes and a reduction in overall healthcare costs by for example reducing the number of emergency admissions to acute hospitals.’ (CSL 2009: Appendix 6, p7)

The ‘care landscape’ or web of care provision for older people living in London is made up of a vast array of private sector companies, voluntary and community organisations, public sector organisations and social enterprises, not to mention the informal care provided by families and friends. However, the London care market is predominantly provided by the private and third sectors. Local authorities directly provide a relatively small share of the care market: about 13 per cent in total. However, they fund the bulk of provision through commissioned services: around three-quarters of home care, and 80 per cent of residential care. While the supply of nursing care is deemed adequate across the city, there is a much tighter supply of residential and home care

for people with dementia (London Councils 2008). Decisions in the way that funding is allocated, including for dementia care and support, vary from one borough to the next. The total care market in London is estimated to be worth £1.4 billion, of which £514 million is in nursing care, £486 million in residential care, and £401 million in home care (ibid). The lack of distinct borders between boroughs in relation to care provision can result in disjointed and fragmented services.

The trend data above shows that London will face a rapid increase in the number of people with dementia in the years to come. The changing demographics in London, particularly the ethnic profile, will bring specific challenges. The way that money is spent on supporting people with dementia will need to be considered carefully in light of these developments.

The sections below address what is currently being done well and highlight where there are problems – now and in the foreseeable future.

The final section makes recommendations for change and indicates where safety nets will need to be put in place in the changing health and social care environment.

3. Health and social care services

For many people, contact with their local GP is the first step in gaining a diagnosis of dementia, but the quality of advice and signposting from GPs in London is extremely mixed. Research in 2009 found that just 31 per cent of the capital's GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia (CSL 2009). A similar picture exists at the national level. Research reported in the British Medical Journal, undertaken by the Medical Research Council (MRC) between 1990 and 2007, found that GPs were recording dementia in a non-specific way and were not differentiating between Alzheimer's disease and vascular dementia, a confusion which could affect long-term treatment decisions and how an individual's disease is managed (Rait et al 2010). The MRC research also revealed that death rates are more than three times higher in people with dementia in the first year after GP diagnosis than in those without dementia. This could indicate that people received their diagnosis at a time of crisis or when the disease had already taken a strong hold.

These findings were reflected in our interviews with service users and providers across London. One manager of a community organisation based in Camden said that a good GP who could identify a case of dementia and 'signpost' the patient on to other services was rare, and the exception to the rule. One carer in Richmond felt that GPs were not taking on the responsibility that they should: 'They need to be educated, and there at least needs to be awareness and information readily accessible to them so they can begin the signposting.' Another interviewee, a service provider based in Kensington and Chelsea, described having a struggle 'every now and then' with GPs. Overall, he did not feel that the opinion of the layperson was taken into account, which he felt was discouraging.

The recent changes in health care commissioning will place more control in the hands of GPs. This could be problematic, given that GPs overall do not have a good record at diagnosing and treating dementia. The challenge is therefore to find ways to ensure GPs are trained to diagnose dementia, refer people to information and advice services, are convinced of the savings they could make through early diagnosis and intervention, and are adequately held to account for the quality of services they commission. We make recommendations in these areas in Section 7.

Good practice example: Information prescriptions

In some parts of the country, 'information prescriptions' have been piloted.⁹ This involves a doctor writing a prescription for a patient to seek advice and information, rather than medication. Being given a written prescription can sometimes spur people to seek advice early on. It also provides GPs with a channel to refer people for more direction and assistance, and helps to link the GP with services in the community.

While there is currently no medical cure for dementia, medical advances mean that medication can delay the onset or minimise the symptoms. For this reason alone, early diagnosis is important. In

9 See http://www.informationprescription.info/materials/workshops/IsleofWight_LeedsMeeting.pdf

addition, diagnosis gives people the opportunity to come to terms with the illness and prepare for the future. It is widely acknowledged that early diagnosis can improve wellbeing and in many cases significantly reduce the long-term costs of care.

Good practice example: Provision of dedicated dementia memory services

Memory services have been successfully piloted in London (including Croydon, Haringey and Westminster) and, as identified by the NAO, 'can provide a cost-effective way of significantly increasing the number of people seen for early diagnosis and intervention' (Pitt 2010). One service provider based in Westminster said that people are probably being diagnosed earlier than they were before because of the memory service. She described how hundreds of patients came to the Westminster Memory Service within a couple of weeks of it opening, highlighting the real need for the service.

Service providers described gaps in care for older people, aged over 80. A service provider, based in Westminster, described how people over the age of 80 or 90 do not get the same level of care as someone who has early-onset dementia. She described how there is 'a sense that you've already had a good innings'. Care for older people with mental health problems also appears to fall behind care for people with other physical conditions. The same service provider described how people with dementia who go into hospital do not receive the same level of care as, for example, someone who is dying of cancer. A report published in 2009 by the Alzheimer's Society found that at least £80 million a year could be saved by improving dementia care in hospitals (Lakey 2009). The report found that poor hospital care had a negative impact on people's dementia and physical health. It notes that the majority of people with dementia leave hospital in worse condition than when they arrived and that a third enter a care home, unable to return home.

Good practice example: An earlier focus on end-of-life care

Westminster funds a dedicated advocacy worker focusing on end-of-life care for people with dementia. Her role involves speaking to people in the early stages of their diagnosis and supporting people to make decisions while they do have the capacity to decide what they want. Exploring options for palliative care and end-of-life care is important, but it needs to be introduced at an early stage. Trained professionals who can handle matters sensitively and in a trusted environment with the service user, and the wider family and care network, have been found to offer an invaluable service, resulting in improved care outcomes in the longer term.

The challenging behaviour that some people with dementia can present with in the later stages of the illness can put pressure on care staff, for carers supporting people at home, but also for carers working in an institutional environment. Despite recommendations around dementia training in the dementia strategy, one of our interviewees described difficulties in regulating care services, explaining that professionals get away with just having a very limited amount of training and that it is down to each individual care home to decide if training is a priority or not. It is clear that enabling carers of people with dementia to be creative and well supported results in better care. This can be improved through training, but also by creating a positive work environment. One interviewee described how, for some service providers, delivery of care too often has a task-based focus which can be at the expense of a wider appreciation of an individual's needs. For many people with dementia, social engagement is lacking.

The dementia strategy has encouraged an approach that focuses on the whole of the dementia care pathway. But problems remain because of a commissioning model that is fragmented and unconnected in places. One service provider with strategic oversight across London commented that for somebody who is commissioning adult mental health services, dementia is a minor element of their portfolio. Similarly, for someone who is commissioning services for older people, dementia forms only a small part of their portfolio. He was concerned that dementia does not receive sufficient attention and that commissioners do not necessarily have sufficient expertise

to be able to think through the whole pathway from early diagnosis through to end-of-life care. Another service provider, based in Westminster, also highlighted this point. She noted that different organisations hold contracts for different parts of the services, and that a more seamless approach would be more helpful. Another interviewee felt that it was important for people with dementia to have their voices included in policy and service development, but that often service providers do not make sufficient efforts to ensure a wide range of voices is heard.

The problems and gaps that are currently present in the provision of health and social care services for people with dementia are serious. Moreover, they are resulting in poor-quality care for some people and increased spending in the longer term. In light of the proposed changes to health and social care, it will be important to ensure that dementia patients do not lose out under the new framework. Measures to ensure accountability of GPs and a more streamlined commissioning process are some of the areas that we explore in more detail in our recommendations in Section 7.

4. Advocacy and advice services

Information and advocacy services for people with dementia are essential, both for service users and their carers. One service provider we interviewed said: 'Information is definitely the biggest issue – it's number one. No question about it.' There are a wide variety of support services available across London for people with dementia, but despite this, some of the service providers we spoke to referred to Londoners with dementia living in the community being isolated, making advocacy support and outreach services even more of a necessity. In our research, we did come across good practice – for example, the support provided by the Alzheimer's Society is highly regarded throughout London. However, on the whole, availability and signposting of advice and advocacy services within London is patchy, as illustrated below.

Interviewees outlined gaps in the provision of advocacy support. These were identified at particular stages, including at the early onset of dementia stage, at the point of diagnosis, on transition from hospital to the home, and from home into residential care. Interviewees described a range of experiences in the kinds of information they received, and the stage at which they received it. One service provider explained that some people receive too much information at the outset and can't assimilate it, whereas other interviewees struggled to get advice and support at the point of diagnosis. A carer based in Richmond felt that an early diagnosis should not preclude ongoing advice and support and said that services needed to be more readily available at every step along the care pathway.

Good practice example: Dementia advisers and 'virtual advisers'

Croydon is using its share of the £60 million allocated for implementing the dementia strategy in 2009–10 to pilot new services. It has used £180,000 to provide a number of dementia advisers (as recommended by the National Dementia Strategy) who work directly with carers or with people who are worried they are developing dementia. As well as benefiting those using the adviser service, this service is being used by Croydon Council to develop an evidence base on which to develop its online information. They plan to use this to create a 'virtual adviser' which would enable carers and service users to access more information online (Pitt 2010). While a 'virtual adviser' may not be accessible to all service users, this approach does go some way towards tackling the problem of insufficient advisers. At the very least, it provides an alternative method for service users and carers to gain assistance.

Advice at transition points is important for service users, but is also significant for carers. Carers experience difficulties at many stages, but research has shown that the most difficult time for people caring for a friend or relative with dementia is the period just before diagnosis. Researchers from University College London found that support for carers currently focuses on the period after a dementia diagnosis.¹⁰ Yet most carers that the academics spoke to felt that more help was needed prior to diagnosis, when it is evident that there is a problem but the carer does not know how to address it. One of the carers we interviewed, based in Richmond, illustrated this point, describing

10 See <http://www.barchester.com/Healthcare-News/Dementia-carers-'need-support-before-diagnosis'/376/3650>

how some carers do not know what services are on offer in their area and need professionals to be proactive in providing support at an early stage.

Good practice example: Linking memory services with support and advice for carers

Haringey offers a service for carers within a memory clinic setting. Carers of people with a recent diagnosis of dementia are offered immediate access to carer assessment within a nurse-led ('Admiral Nurse') clinic. The service is developing a carer satisfaction outcome tool, but notes that a steady increase in referral rates has already been seen.¹¹ As continuity of service provision and fragmented services appear to be problems in London, we welcome the development of a service that links up support for carers and service users at the same point.

Our interviewees stressed the importance of continuity and consistency in advocacy provision and also noted that the support process for people with dementia can often be lengthy. Maintaining contact with clients can also be time-consuming. Advocacy services for people with dementia often carry out more face-to-face contact with clients, as people often find it hard to relate well over the phone. Outreach support is a crucial lifeline for many people with dementia, in particular during the middle stages of dementia, but it can last for many years. For people with dementia, a consistent service is essential. One service user said: 'This particular one, he'll ask me questions and he'll think about the answers I give him. He'll listen and he'll give me suggestions as well. I hope I don't lose him.' But under a commissioning model consistency can be problematic. One advocacy services provider in Westminster described how her role had changed three times in the last few years, because of funding – she described how the situation was 'getting harder and harder'.

Befriending and advice services are an essential lifeline for many people, but providers often struggle to meet the needs of their service users. Befriending services do exist in pockets around London. Where they exist, they can offer an invaluable service that taps into a person's social and cultural needs, rather than taking a purely task-focused or health-oriented approach. One service provider working at a befriending service in Camden described how their service fills a gap: without it, people can become invisible and then if a problem arises they struggle to link into support services. Another service provider, based in Westminster, stressed the importance of dementia advisers. Despite referring to a consistent advice service as the 'perfect scenario', she also stressed that it works differently in reality because dementia advisers tend to have too many clients.

The personalisation agenda and the introduction of personal budgets elicited mixed responses from interviewees. Personal budgets for older people with dementia are being piloted in some parts of London, including Westminster. Personal budgets allow older people to pay for services to improve wellbeing and to meet individual social interests, as well as meeting care needs. Some interviewees acknowledged the benefits of an individualised service, but caution was raised about capacity to handle budgets, especially given the deteriorating nature of dementia as an illness. The Department of Health has issued guidance on how personal budgets can work well for older people, including for people with dementia, who may 'require individual approaches and solutions' (Department of Health 2010b). One dementia advocate, based in Westminster, was positive about personal budgets, but cautioned that they can be stressful for some service users.

The provision of advocacy and advice services is patchy in London and will need to be strengthened considerably in order to meet the needs of the growing numbers of people with dementia. While a focus on particular transition points in the care pathway is needed, it's clear that a consistent approach from diagnosis right through to end-of-life care will be paramount. In the future, commissioners will play an increasingly key role in shaping and supporting these services.

11 See: http://www.dementia.dh.gov.uk/_library/downloads/Objectives_resources/objective7/Obj_2_and_7-Admiral_Nurse_led_clinic.doc

5. Support for social activities and interaction in the community

In London, a balance needs to be found between services that provide specialist care and those that are inclusive and allow dementia to be normalised within the community.

Given the high prevalence rates of dementia among the wider population, it is not surprising that the social interests of people with dementia are extremely diverse and wide-ranging. In contrast, activities for dementia patients in London are often very limited. Some of the service users we spoke to expressed frustration at not being supported to carry out activities that they enjoyed before they had dementia – examples given included attending lectures and visiting galleries. It was felt that there should be more opportunities available for a broader range of services for people with dementia, especially in a vibrant and diverse city like London. In addition, some service users and providers commented that they didn't want to spend their time only with other people who had dementia, but wanted to be able to engage in community activities that interested them. Some service users raised the issue of a lack of intellectual stimulation and the struggle they had in maintaining their particular interests and hobbies. A service provider based in Westminster commented that resources tend to be spent on meeting care needs, rather than focusing on an individual's social activities. She noted that many people with dementia want to talk about and engage in the activities they enjoyed in the past.

Some service providers also referred to the different support needs experienced by men and women. It was noted that in some areas day care centres tended to put on activities which appealed more to women, and that services directed at men with dementia could be beneficial.

Community-based activities are an essential lifeline for many people with dementia and their carers, but many smaller community organisations struggle to provide these services, often due to funding cuts and commissioning frameworks and priorities. One service provider we interviewed felt that smaller community organisations were losing out to bigger ones. Another interviewee, with a strategic remit across London, expressed the concern that it would be simpler, particularly for a new commissioner, to commission more residential care beds than to develop and sustain community-based care and support services. Efforts to support community-based activities would have important long-term financial savings, particularly by preventing unnecessary hospital stays. CSL has noted that older people with dementia occupy 20 per cent of acute hospital beds across England, when in fact around 70 per cent of these may be medically fit to be discharged (CSL 2009).

Good practice example: Opportunities to engage in a broad range of activities

Open Age arrange a broad range of activities for older people in London. This includes a range of classes different to the traditional day centre.¹² For many people with dementia, an opportunity to engage in a broader range of activities is welcome. Personal budgets also provide service users with the opportunity to tailor their service needs to these sorts of activities. One service provider mentioned a client who was using his personal budget to attend debating sessions.

Specialist services are essential, but dementia also needs to be recognised and better understood within the community. Community support and activism is at the heart of the Conservatives' vision of the 'big society'.¹³ Some of our interviewees acknowledged the value of the 'big society', particularly for the part it plays in creating community awareness about dementia and reducing stigma. A more supportive community would allow people with dementia to be more engaged in local activities and prevent isolation. One interviewee commented that people with dementia still have the right to be part of their local community. She explained that: 'actually it's the barriers of the way the world engages with them that can make them [feel] isolated much sooner than they actually need to be or want to be.'

¹² See <http://www.openage.co.uk/>

¹³ Nat Wei, the government's chief adviser on 'big society' describes it as: 'Building the capacity of citizens, encouraging national collective activity, and a constant negotiation between the boundaries of civil society, citizen and government.' See <http://www.guardian.co.uk/society/2010/jun/22/nat-wei-big-society-adviser-conservatives>

Good practice example: Dementia Friendly Communities

Innovations in Dementia, a community interest company, has set up a project called 'Dementia Friendly Communities'. The project is seeking further funding to carry out work to find out what makes a 'dementia-capable community'. As well as engaging with local people, shops and businesses, the project hopes to support people with dementia to be in contact with people from other age groups.¹⁴ Innovations in Dementia also practises user-involvement: people with dementia influence the projects that are run, and the organisation supports people with dementia to engage with others, particularly policy and service developers, to make sure that their views can influence care and support services and the wider policies that affect them. Involving people with dementia helps to spread a wider message about 'living well with dementia', as advocated by the National Dementia Strategy, by openly recognising the part that people with dementia can play in shaping and improving service delivery in their community.

In London, low-level training and awareness-raising with local retailers and in community settings is lacking. The 'big society' may go some way towards achieving greater public awareness and recognition of dementia, particularly within family and community networks. The Joseph Rowntree Foundation has noted that debates about transforming social care must consider 'the wider networks and dynamics involved in providing and receiving support through family, friends and community' (Bowers and Gandhi 2008). Nevertheless, a focus on community support and involvement should not eclipse the need for investment in training and specialist services, as these are essential given the complexity of the condition.

6. Providing services and support for a diverse community

The complications that present with dementia can be compounded by a range of factors, such as low health status, social deprivation, alcohol or substance abuse, barriers relating to ethnicity, discrimination, living alone and social isolation. Cross-cutting diagnoses and multiple inequalities introduce a range of additional challenges for service providers who support people with dementia. London, with its diverse BME communities and high prevalence of people with poor mental health, particularly in socially deprived areas, faces particular challenges of this kind. While there are some areas of particularly good practice, and innovative approaches to tackling these cross-cutting problems, it is still difficult to effect substantial change.

Some London boroughs face huge challenges in providing adequate services for harder to reach groups, including poorer residents and people from BME communities. With a large number of BME groups, covering more than 300 spoken languages and a multitude of faiths and traditions, the needs of older people in London are becoming increasingly complex. One service provider, based in Kensington and Chelsea, referred to incidences of racial and gender discrimination that he was aware of. Some of the service providers we interviewed expressed difficulty in providing support for people with dementia from BME groups: one, based in Westminster, explained that each BME group has a different understanding of what dementia is, with some having very little knowledge of dementia and some having no definition of dementia at all. Specialist outreach services play an increasingly important role in targeting hard to reach groups and will continue to do so in the future. But definable outcomes of outreach services are sometimes harder to pinpoint, and so to achieve funding for.

Good practice example: A local Alzheimer's Club or Café

The London Borough of Haringey is divided into two very different localities: one very affluent and one very deprived. After the success of an 'Alzheimer's Café' in the west of the borough, 'Tom's Club' was set up to meet the needs of the population in the east of the borough, where there is very little in the way of support services for people with dementia

¹⁴ See: http://www.innovationsindementia.org.uk/Newletter/InnovationsInDementia_BrainWaves_December2009_January2010.pdf

and their carers. The club provides peer support, education and information, and is a social outlet for people with dementia and their carers. The local population is ethnically very diverse so it was acknowledged that to provide a service that meets the needs of such a range of people has been a challenge. Attendance is monitored and the client group is surveyed in order to evaluate and assess the service. The initiative was set up with private funds but is also sponsored by local tradesmen and businesses (including Tottenham Hotspur Football Club), so is a resource of the local community.¹⁵

Dementia in people from BME groups is not always recognised. Minority ethnic groups are at far greater risk of misdiagnosis and delayed treatment than other mental health service users. In particular, higher rates have been found among Black Caribbean older people, even though the recognition of dementia is lower among South Asian and African Caribbean people than among the population as a whole (Lane and Hearsom 2007). One service provider, based in Kensington and Chelsea, commented that he was aware of frequent misdiagnoses. Another interviewee, based in Westminster, described how the language used by professionals actually has to be meaningful to the specific community group in question. She felt that organisations in London were a long way from being able to deliver appropriate dementia services, information and representation to different BME groups.

Short-term funding can impact on the sustainability of local services. Because many operate in isolation, this can result in patchy coverage, leaving some people without access to any services. One interviewee working across London cautioned that any change or support has to come from within the community and not by another organisation 'parachuted in' to provide services for people from minority groups. She felt that, ideally, larger organisations should be working in partnership with local community groups. Collaborative work amongst community organisations (including information sharing and joint working) was flagged up by the service providers we interviewed as being an important way of engaging harder to reach groups. But this poses a number of challenges – in particular, organisations collaborating to bid for funding require support in how to work together effectively. One service provider, based in Westminster, highlighted the gap in this area, stating that until community organisations are willing to work with other local community organisations from different BME groups it will be difficult to combat all the stigmas and taboos that are associated with dementia.

Good practice example: Mapping services for BME communities

The National Mental Health Development Unit (NMH DU), launched in April 2009, is funded by both the Department of Health and the NHS to provide national support for implementing mental health policy. As part of their remit NMH DU has mapped projects and resources that provide support to people from BME communities.¹⁶ The compilation is a useful resource. It also highlights that services for older people from BME communities are predominantly met by voluntary, rather than statutory, services.

Chapter 2, above, demonstrated how projections of people with dementia are set to increase and that this will have particular significance for London's BME communities. Our findings here illustrate that there are currently many gaps in the provision of support for people from hard-to-reach groups, particularly from BME communities. Given the future projections on ageing, it is clear that ongoing and improved support for BME groups should be a pressing concern for policymakers and commissioners in the coming years.

15 See: http://www.dementia.dh.gov.uk/_library/downloads/Objectives_resources/objective5/Toms_Club_Alzheimers_Cafe.doc

16 For more information, see <http://www.nmhdu.org.uk/silo/files/bme-national-mapping.pdf>

7. Conclusions and recommendations

Major changes to health and social care are currently being proposed by the Coalition government and so our recommendations are made in the context of a changing policy landscape. Conclusions are drawn from our research exploring the situation in London, but recommendations are not exclusively focused on the capital – these approaches may be relevant to other parts of the UK.

ippr's findings demonstrate that **GPs in London who can identify and provide adequate advice for people with dementia are the exception, rather than the rule.** There is a serious deficit in GPs' awareness of dementia, which can result in a failure to diagnose and signpost, in turn risking crisis intervention at a later stage and increased costs in the longer term. It is clear that the National Dementia Strategy's aim to promote early diagnosis is still being inadequately addressed, resulting in poor-quality primary care for patients and placing a larger burden on secondary care.

Recommendation: Better training and support for GPs in order to improve the delivery of primary care

- GP training on dementia needs to be embedded early on in medical training. The training needs to focus more on identification of different types of dementia and should specifically aim to understand the needs and experiences of harder to reach groups, particularly people with additional diagnoses of substance misuse problems as well as people from BME groups. Training also needs to have a greater focus on end-of-life care and palliative care for people with dementia.
- Training for GPs needs to be ongoing and to be regularly reinforced and updated. Voluntary and community groups have a key role to play in delivering training packages to GPs in order to provide the best insight into local needs and to identify gaps in services.
- Embedding advice services in surgeries will provide additional support for GPs and assist with signposting. Co-location of support services in surgeries will also help to link support for patients with much-needed support for carers.
- 'Information prescriptions' have been piloted in some parts of the UK as a method of signposting people towards support services and can spur people to seek advice early on. They also provide GPs with a channel through which to refer people for more direction and assistance. Wider roll-out of this pilot is recommended.

Systems need to be put in place to strengthen the links between health and social care to ensure a more integrated service and a seamless care pathway for people with dementia.

Under the new commissioning framework, it will be essential that health and social care commissioners are held truly accountable for working in partnership with each other. Safety nets will need to be put in place to ensure that people with dementia do not lose out. The Department of Health has stressed that at the heart of its plans, 'the principle of autonomy lies alongside that of accountability' (Department of Health 2010a). While the need for health and social care commissioners to have autonomy is acknowledged, it will be essential under the new commissioning framework that commissioners are held to account, and that good practice is driven forward.

Commissioners of both health and social care will also need to establish strong links and work closely together in the future. Forging strong relationships will help to flag up the need for prevention at an earlier stage and thereby reduce crisis intervention and the unnecessary burden that is placed on secondary level care. Local authorities carry out a preventative role in commissioning and delivering public health services, which in turn makes cost savings for primary care.

The NHS Commissioning Board will hold GP consortia to account for the quality outcomes they achieve and for financial performance, but will have the power to intervene only when there is evidence that consortia are failing. This leaves a gap in the level of scrutiny that GP consortia will be subjected to. Health and Wellbeing Boards will be set up in every upper-tier local authority, allowing commissioners to come together on a geographical basis, but these boards will not have a

health scrutiny function. Instead, the department proposes to give local authorities a new freedom to discharge health scrutiny powers in the way they deem to be most suitable.

It is clear that systems must be put in place to ensure proper scrutiny of the commissioning process and promote joint working between commissioners of health and social care.

Recommendations for integrating health and social care services

- Health and Wellbeing Boards will play a key role in promoting and supporting joint working between commissioners of health and social care. The new boards should include dementia as a priority in their local Joint Health and Wellbeing Strategies.
- We recommend that community and voluntary organisations working with people with dementia engage with their local Health and Wellbeing Board and attend and engage in public meetings, and in doing so influence decisions and highlight the pressing care and support needs in their local area.
- Co-location of health and social care in the same buildings has been achieved in some parts of the country. This needs to be rolled out further to ensure greater information sharing and close working between practitioners.

Recommendations for social care commissioners

- We urge local authorities to retain the role of the health overview and scrutiny committees to ensure that decisions made by commissioners are properly scrutinised.
- A system that is driven by patient need and choice is important for holding commissioners to account. Under the current system, which increasingly employs personal budgets, patients have more choice and corresponding purchasing power. Dementia patients, or their carers, can now hold budgets to pay for individual support, such as a personal care assistant to allow that person to remain in their own home. Despite this, some reservations have been expressed around the capacity for people with dementia, and their carers, to hold budgets. There are many ways that budgets can be held (such as notional budgets held by advocates and family/carer involvement) and these should be increasingly offered and a variety of options explored for all patients. For people with dementia, personal budgets need to be reviewed on a case-by-case basis and monitored closely for suitability as the condition progresses.

Recommendations for health care commissioners

- The NHS Commissioning Board should ensure that the quality of dementia care is included in the new outcomes framework by which GP consortia will be held to account.
- There is a risk that GP consortia may not be convinced of the benefits of investing in early-intervention approaches to dementia care. One of the new 'pathfinder' GP consortia should pilot an early-intervention approach to dementia care. This could provide the necessary evidence base to reassure future consortia that commissioning dementia services is a worthwhile investment, which can result in savings further down the line.

It is clear that proposed changes to health and social care will result in increased reliance on voluntary and community services, and yet **some organisations are struggling to receive commissioned funding and find partnership working and forming consortia to collectively bid for funding extremely challenging**. Local community-based organisations will need help in setting up and bidding for contracts. In addition, measures will need to be put in place to help people who are purchasing services to navigate the market.

Recommendation: An approved menu of providers for commissioners

- Despite there being some excellent voluntary and community sector organisations delivering services for people with dementia, there are clearly many gaps in provision and the quality and level of the service varies. An approach that ‘kite-marks’ approved providers could be introduced in order to assist commissioners. Alternatively, audits of dementia services may provide more detailed information on quality and design of services. This could be done by local authority Health and Wellbeing Boards, or by the Care Quality Commission. The cost of such an audit should not be borne by providers, many of whom are too small to cope with added burdens.

Recommendation: Greater support for voluntary sector to form consortia

- Community organisations need support in collaborating to bid for commissioned funding. Consortia can offer cost-effective ways of providing services and promote good practice and information sharing. CSL has provided this support but proposals are now underway to wind down this service. While it is recognised that CSL is unlikely to remain in its current format, it is essential that the element of CSL that supports partnership working is protected. In today’s changing climate, it is not clear who might take on this role. However, local authorities may be well placed to coordinate and deliver support to organisations wishing to collaborate.

Recommendation: Voluntary and community organisations need to excel in specific areas

- The new commissioning model puts greater pressure on voluntary and community organisations and they will need to respond by focusing and improving the quality of their services. Service providers will need to be able to show that they can offer consistent services with clearly definable outcomes, particularly for advocacy and outreach services.
- Voluntary and community sector organisations are well placed to deliver targeted and specialised training. Designing and delivering training packages that GP consortia can commission will be an important area for some organisations to develop.

Service provision for people aged over 80 with dementia is weak compared to services for people with early onset dementia and services for older people with physical health conditions. New proposals have been made to bring mental health care standards up to that of physical health. This is a welcome development but stigmas of old age and of mental health still persist, and the combination of the two repeatedly results in poor quality of care in later life.

Recommendation: Renewed efforts to tackle stigma and misunderstandings relating to old age and mental health

- Greater, widespread public awareness about dementia will go some way towards normalising and accepting dementia within society. Awareness-raising campaigns that project a positive approach to dementia (both nationally and locally), intergenerational activities in schools and community groups, community training (with retailers, the transport sector, landlords and so on) and community information-sharing schemes could help to raise greater awareness and prevent stigma. The government’s move towards the ‘big society’ seeks to encourage greater community action and involvement. It would certainly be beneficial if the drive to encourage communities to be more active resulted in greater support for people with dementia, and increased awareness of people’s needs.
- Community support and care is important but specialist care, particularly in the later stages of the illness, remains paramount. The National Dementia Strategy makes recommendations relating to improved training for health professionals. As in the case

of training for GPs, as set out above, voluntary and community organisations are well placed to offer training packages on dementia. These are also particularly needed in institutional care settings and in palliative care services.

Service provision for older BME Londoners with dementia is struggling to meet current needs. Moreover, the number of over-80s in London from a BME background is projected to almost triple between 2010 and 2031, rising from 28,600 to 80,000. Over the same period, the number of white over-80s in the capital is expected to increase by 21,600 – a rise of just one-third. The Department of Health refers to the need for ‘patient-centred’ commissioning (Department of Health 2010a) but it is clear that commissioners will need to work hard to ensure user participation of older people with dementia, particularly those from harder to reach groups, in the design and delivery of services.

Recommendation: Cross-cutting inequalities need to be a central consideration for commissioners and community organisations

- Commissioners should favour services that adopt a ‘co-production’ model¹⁷ to ensure that people with dementia are engaged in the delivery of their care. If BME groups are involved in the design and delivery of services, they are likely to be more culturally relevant.
- Commissioners will need to recognise the ongoing value and importance of outreach work and specialist services which do not always have easily definable outcomes.
- Services should be provided by communities themselves rather than by outside providers ‘parachuted in’. This will ensure information and services are provided in a more culturally relevant format for hard-to-reach groups.
- Health professionals need specialist, ongoing training in the support and care needs of people from BME groups.
- Misdiagnosis and delayed treatment needs to be tackled. This requires specialist training of health professionals and ongoing challenges to stigma and discrimination. Voluntary and community organisations should ensure that people with dementia and their supporters are made aware of their potential rights under the Equality Act 2010, and be supported to press for their rights if necessary.

The shift towards the government being more enabling, rather than directive, in its approach towards health and social care will place greater control and responsibility in the hands of GP consortia, local authorities and community and voluntary services. This brings advantages by allowing for a more flexible service that can respond to local patient needs. But the projections of the growing numbers of people with dementia indicate the urgent need to improve and advance care and support in this area. It is a serious concern that there are currently so many gaps and problems in service delivery, particularly at the primary care level.

Commissioners have a crucial role to play in ensuring a smooth and integrated care pathway for people with dementia, particularly for those from harder to reach groups. Greater accountability, and incentives to recognise long-term cost savings, will go some way towards creating a safety net for people with dementia, many of whom lack the ability to advocate for their own care and support needs. Community and voluntary organisations are now operating in a climate in which they will need to become adept at meeting the needs required by commissioners and be able to prove that they are in tune with their local community. London faces unique challenges, but more widely there is no doubt that this is an area that will require much attention and scrutiny across the entire country in the years to come.

¹⁷ Where the citizen and the professional both play a role in the design and delivery of a service, policy thinkers have typically talked about ‘co-production’. ‘Co-production’ has been defined by the Prime Minister’s Strategy Unit as ‘a partnership between citizens and public services to achieve a valued outcome’ (Horne and Shirley 2009).

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