

DEMENTIA - THE GREAT HEALTH AND SOCIAL CARE CHALLENGE FOR THE 21ST CENTURY

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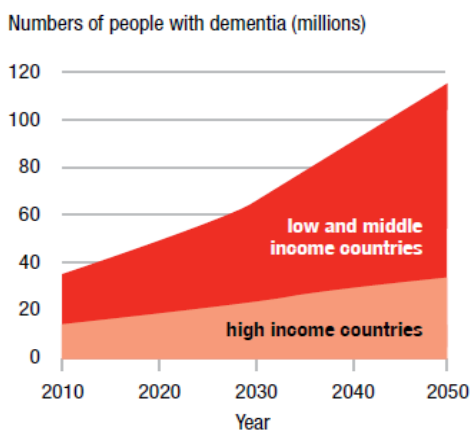
Scope of the paper

This paper aims to summarise the challenges posed by dementia to health and social care systems and society more widely in the first half of the 21st Century and strategies for their potential solution. To illustrate this, we will first consider the development of policy and system change in the UK to date. Second we will consider whether there are lessons in the development of policy that might be learned from the successes in building the priority for action on dementia. Third we will look critically at dementia in the context of secondary mental health services.

The challenge of dementia

There can be no doubt that dementia is one of the greatest societal challenges that we face as we start through the 21st century. Its personal and societal impacts are greater than those health conditions such as cancer and heart disease that preoccupied the last century;ⁱ it is a challenge that transcends barriers of health, social and family care. Dementia is a challenge at international, national, regional and local levels as well as the personal. It is in all ways exceptional in terms of size, cost and current and future impact. There are 750,000 people with dementia in the UK now and that will double in just 30 years.ⁱⁱ The overall cost is currently £17 billion, with that set to treble to over £50 billion in the same 30 years.ⁱⁱⁱ

There is also no doubt that it is a worldwide phenomenon. The best estimations available suggest that there are around 34 million people with dementia worldwide, rising to 81.1 million by 2040 and to over 100 million by 2050.^{iv} This is an issue for the developing world as well as the developed, even now around a half of these cases are in Asia and that that proportion will rise swiftly with time. The profound negative impacts of this devastating group of illness on people with dementia themselves, their families, and in terms of health and social service use are not in doubt. Dementia is highly stigmatised and universally feared, with studies suggesting that it is one of the very few illnesses rated as “worse than death”.^v



It is equally the case that there is a widespread underestimation of the positive things that can be done to help people with dementia live good quality lives with dementia. In the last decade it has become clear that there are a multiplicity of positive interventions that can promote independence and give people with dementia and their family carers good life quality. Things that can enable individuals and their friends and families to adapt to the challenges of dementia and steer a course in the 7 to 12 years that they might be living with dementia that avoids crises and harm and that promotes wellbeing for all involved. The majority of these are simple

approaches to good quality diagnosis and care planning with the delivery of psychological, social, educational and supportive interventions.^{vi}

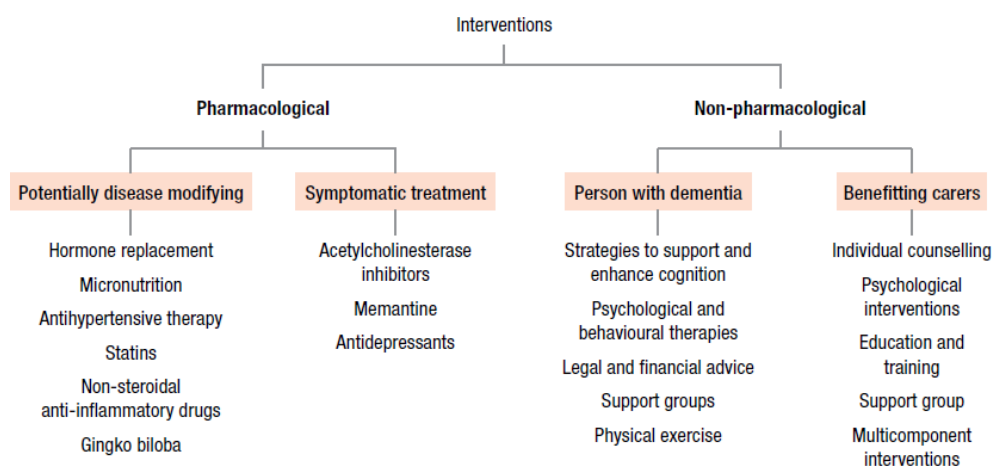
However, it has also become clear that the large majority of people with dementia and their family carers do not benefit from these positive interventions and supports. In fact systems often seem to have been designed to result in the avoidance of diagnosis and the consequent denial of care. A fundamental flaw in the current system is that only about a third of people with dementia receive a diagnosis of dementia; and then when they do it is usually late in the disorder, often at a time of crisis when it is too late to prevent the harm that has been caused to the person with dementia and their family.

Dementia - an emerging priority

So dementia is one of the most severe and devastating illnesses we face. It is also very common and the numbers and costs can be predicted to at least double in the next 20-30 years. It is demographic change with increasing longevity that drives these changes. As more people enter the population at risk (ie increasing age over 65), so the overall prevalence and incidence will rise. Given that the biological processes underlying Alzheimer's disease start 20-30 years before the first cognitive symptoms occur, we can be clear about the coming increasing challenge since the new cases in the next 25 years already have the progressive pathology acting in their brains. It is predominantly a disorder of later life, but in the UK at least 15,000 people under the age of 65 have the illness; around 15,000 people from minority ethnic groups have some form of dementia, but this number is set to rise sharply as these populations age. Dementia has a devastating impact on those with the disorder, but it also has profound, negative effects on the family members who provide the majority of all care. Family carers are often old and frail themselves, and suffer high levels of care burden, depression and physical illness, and a diminished quality of life.

Dementia is a terminal disorder, but people can live with it for 7–12 years after diagnosis. The challenge we have is how to enable people with dementia and their carers to live as well as possible, maximising their quality of life. The National Audit Office identified problems in the current systems of health and social care for dementia. Its report *Improving services and support for people with dementia* estimates that approximately two-thirds of people with dementia do not receive a formal diagnosis – or have contact with specialist services – at any time in their illness.^{vii} This is a diagnosis and treatment gap that has been confirmed at a global level by the latest World Alzheimer's Report.^{viii} This report also makes clear the value of early diagnosis and intervention. It is of concern that such diagnosis and contact, when made, often only occurs late in the illness and when the person with dementia is in crisis – so the opportunities for choice, harm prevention and maximising quality of life are limited. If dementia is not diagnosed, the person with the illness and their family carers are denied the possibility of making choices themselves. They are unable to plan for their future and do not have access to the help, support and treatments (social and psychological, as well as pharmacological) that are available.

Contrary to popular belief, a great deal can be done to provide help for people with dementia and their carers (this has been well summarised in the NICE/SCIE clinical guideline on dementia). While there are undoubtedly potential negative reactions to diagnoses^{ix}, the balance is very much in favour of making these early – the earlier they are made, the better^x. There is clear evidence that providing people with a diagnosis decreases their levels of depression and anxiety^{xi}.



There is a real problem in service planning in terms of the lack of routinely collected data on dementia services in the UK. The data available is limited, but UK activity in terms of the diagnosis and treatment of people with dementia is generally low but with a 30-fold variation in activity between the lowest and highest functioning PCTs. There are also significant variations between areas that are not explained by the numbers of people with dementia in those areas. International comparisons suggest that the UK is in the bottom third of European performance^{xii}, with less than half the activity of France, Sweden, Ireland and Spain. The National Audit Office's report, and that of the Public Accounts Committee subsequently, recommended that services need to be redesigned so that dementia is diagnosed early and well, and people with dementia and their family carers can receive the treatment, care and support that will enable them to live as well as possible with dementia. Transforming the quality of life of people with dementia is also about empowering those people to make choices about what they want, and enabling them to care for themselves. Services need to put people with dementia and their carers at the heart of planning their lives. In addition to adequate services being in place, people need to be informed and supported to make choices. There are clear suggestions that this often does not happen in the UK at the present time.

The policy framework

The realisation that all is not well in the health and social care provided for people with dementia has developed clarity and momentum over the past decades. Services for people with dementia are complex, and include primary health care, specialist services in mental health (eg old-age psychiatry), care provided in general hospitals (eg geriatrics and neurology), as well as social care commissioned and provided by both local authorities, the voluntary and independent sectors, and for-profit providers of home care and care homes. Most important of all is the care provided by families informally. There are examples of excellent dementia care provided by all of these agencies, and also problematic care within each. Strategy and policy evolves and, as the evidence base has grown, so the last decade has seen a growing acknowledgement and understanding of the challenge posed by dementia and the need for service improvement. To illustrate the building blocks, details of relevant UK reports and policy include:

Forget me not: Mental health services for older people (Audit Commission, 2000) - key findings included:

- Only a half of GPs believed it important to look actively for signs of dementia and to make an early diagnosis.
- Less than half of GPs felt that they had received sufficient training in how to diagnose dementia.

- A lack of clear information, counselling, advocacy and support for people with dementia and their family carers.
- An insufficient supply of specialist home care.
- Poor quality assessment and treatment, with little joint health and social care planning and working.
- **They found little improvement when reviewing change two years later (Audit Commission, 2002).**

The National Service Framework for Older People (Department of Health, 2001) - included a chapter on mental health and older people including a consideration of dementia, advocating:

- Early diagnosis and intervention.
- That NHS and local authorities should review arrangements for health promotion, early detection and diagnosis, assessment, care and treatment planning, and access to specialist services.
- The provision of “integrated” and “comprehensive” services.
- **Reviewing progress, this appears to have had little positive impact on services for people with dementia and their families (Banerjee et al, 2010).**

Everybody’s business: Integrated mental health services for older adults: a service development guide (Care Services Improvement Partnership, 2005) – this set out the essentials for a service that works for older people’s mental health including:

- Memory assessment services to enable early diagnosis of dementia for all.
- Integrated community mental health teams whose role includes the management of people with dementia with complex behavioural and psychological symptoms.
- **Little effect since there were no levers to mandate such service provision.**

Dementia: Supporting people with dementia and their carers in health and social care a joint clinical guideline on the management of dementia (National Institute of Clinical Evidence and Social Care Institute of Excellence, 2006) - key recommendations included:

- Integrated working across all agencies.
- Memory assessment services as a point of referral for diagnosis of dementia.
- Assessment, support and treatment (where needed) for carers.
- Assessment and treatment of non-cognitive symptoms and behaviour that challenges.
- Dementia care training for all staff working with older people.
- Improvement of care for people with dementia in general hospitals.
- **A useful, if unprioritised, list of things that might be done but are generally not done, did not prompt change in services but showed what might be done.**

The Dementia UK Report (Knapp et al, 2007) – published by the Alzheimer’s Society, the report’s key findings included:

- The number of people with dementia in the UK – 700,000.
- The projected number of people with dementia in the UK – doubling in 30 years to 1.4 million.
- The costs of dementia £17 billion per year.
- Low level of diagnosis and management of dementia in the UK.
- High variation in activity between areas in the UK.

- The recommendation that dementia should be made an explicit national health and social care priority.
- The need to improve the quality of services provided for people with dementia and their carers.
- **Positive impact in terms of the government accepting the figures and the need to do something to improve care, with the next two reports formed the priority for making dementia a priority and developing national policy.**

Improving services and support for people with dementia (National Audit Office, 2007) - this report by the external auditors of UK governmental spending was profoundly critical of the quality of care received by people with dementia and their families. Its findings included:

- The size and availability of specialist community mental health teams was extremely variable.
- The confidence of GPs in spotting the symptoms of dementia was poor and lower than it had been in 2000 (down to a third).
- Deficiencies in carer support.
- Services are not currently delivering value for money to taxpayers or people with dementia and their families.
- That too few people are being diagnosed or being diagnosed early enough.
- Early diagnosis and intervention is needed to improve quality of life.
- Services in the community, care homes and at the end of life are not delivering consistently or cost-effectively against the objective of supporting people to live independently as long as possible in the place of their choosing.
- The need for a 'spend to save' approach, with upfront investment in services, for early diagnosis and intervention and improved specialist services, community services and in general hospitals resulting in long-term cost savings from prevention of transition into care homes and decreased length of hospital stay.
- **Required high level response from government and very much helped in the prioritisation of dementia, forming part of the rationale for the National Dementia Strategy.**

Improving services and support for people with dementia (Public Accounts Committee [PAC], 2008) – NAO reports are followed up by the PAC which is the senior committee of the House of Commons and which holds to account by interrogation the heads of the civil service responsible for government spending, in this case the Department of Health. At the committee's public hearing on 15 October 2007 the NHS Chief Executive and other senior policy makers from the Department of Health were questioned on the NAO's criticisms, the PAC's subsequent recommendations included:

- Dementia should be made a high priority for the NHS and Social Care
- The need for explicit national ownership and leadership
- Early diagnosis
- Improving public attitudes and understanding
- Co-ordinated care
- All improvements to benefit carers too
- Improvements in care in care homes
- Improvements in care in general hospitals

The Government's response to the PAC report was to accept virtually all the conclusions and recommendations of the committee, assuring the committee that their findings would be fully addressed in a new National Dementia Strategy. In preparation for this there was a one-year programme to develop a National Dementia Strategy and implementation plan.

The above demonstrates the development of policy over time. The first four initiatives above had much to commend them in terms of their content but achieved little in the way of tangible benefit for people with dementia and their carers. Seen within the framework of innovation, they can be seen as a form of sustaining (if directly unproductive) innovation. They can however be seen as a necessary set of steps to initiatives 4 to 7 which made the difference between there being a National Dementia Strategy and there not being one. Taken together, to continue metaphor, these steps can be seen as disruptive innovation creating a new set of services by applying a different set of values (ie early diagnosis and intervention), allowing further sustaining-innovation to improve quality of care from there on.

Enabling disruptive innovation - making the case for a national dementia strategy

So dementia was long a 'Cinderella' element of health and social care systems, suffering from a triple discrimination coming from that associated with: age, mental disorder, and dementia itself. What is it that allowed Cinderella to come to the ball? How was the possibility of disruptive innovation in service delivery achieved so enabling the possibility of rapid major improvement in quality of care. In effect, there has been a three way pressure which acted together to bring dementia out of the shadows and into the minds of the public and politicians.

1. The Facts

Step 1: What are the numbers? Advances in research into case definition and population based surveys have given solid information of the epidemiology of dementia. In the UK the leading voluntary sector advocacy organisation for people with dementia and their carers, the Alzheimer's Society, commissioned independent researchers at the Institute of Psychiatry and the London School of Economics to synthesise all available data on the prevalence of dementia using a Delphi approach. This was then used with local and national demographic data to generate a definitive number of people with dementia in the UK (700,000) and in each individual health and social service funding area (Knapp et al 2007). There is no more powerful tool than locally derived and relevant data.

Step 2: What are the costs? A primary concern of government is cost. Knowledge about what an illness is already costing and how that money is being spent is very powerful. Using best available national measures of service use in dementia and the costs of services with the numbers generated above can give you the costs of dementia. The issue of how to cost the work done by family carers is difficult and the status of work forgone in order to care (opportunity costs) is controversial but a pragmatic approach making the best of data that will have holes in them is needed. In the Dementia UK report this was costed at minimum wage. This yielded a cost of £17 billion per year, a sum equivalent to a fifth of the whole health budget and more than heart disease, stroke and cancer combined. This helps to gain the attention of policy makers and politicians. The majority of these costs (£7 billion) were in care home costs for people with dementia.

Step 3: What about the future? All countries have population projections and the numbers with dementia in the next 20-30 years can be predicted because those people will already have the pathology at work. It is the work of politicians and policy makers to think strategically, so a measure of future threat is of use. The figures generated above allow for the calculation of projections of the growth in numbers and costs of dementia into

the future. In the case of the UK this meant that in just 30 years (ie in 2027) there would be a doubling of the numbers of people with dementia to 1.4 million and a trebling of the costs to over £50 billion per year (Lowin et al 2001). These figures make clear the need for a strategic plan for dementia and strongly support the need for this to be at a national rather than a local level.

Step 4: Is it broke? The old maxim “if it ain’t broke don’t fix it” is of importance here. If we have excellent quality diagnostic, treatment and care services for people with dementia and their families then the need is to preserve these and grow them. If however we find our services are not “fit for purpose” then there may be a need for more radical changes. In the UK an analysis of prescription of anti-dementia medication (prior to recent NICE guidelines) showed the level of UK diagnosis and treatment of people with dementia was generally low with a 24-30 fold variation in activity between highest and lowest activity by area. International comparisons suggested that the UK is in the bottom third of European performance with less than half the activity of France, Sweden, Ireland and Spain (Waldemar et al. 2007). These data make the case for the system being “broke”.

Step 5: They would say that wouldn’t they? Independent corroboration is vital. The data cited above were generated by a pressure group for dementia (the Alzheimer’s Society) and researchers dedicated to making the case for dementia. To gain credibility it is very useful if dispassionate external assessment can come to the same conclusions. In the UK a vital spur to the government making dementia a national priority were the analysis carried out by the Government’s own auditors, the NAO (2007) and the subsequent enquiry by the UK House of Commons’ PAC (2008) described above. These confirmed the findings of the Dementia UK report providing vital external validation.

2. The Faces

It was positive that people with dementia, such as Ronald Regan and Terry Pratchett were willing to come forward and speak about their illness generating a different image of dementia, not one focussed on the total dependency of real life. Even more important were the voices of people with dementia and carers that were heard as part of the evolving discourse facilitated by the Alzheimer’s Society so that politicians and policy makers got to experience the realities of the illness first hand and personally.

3. The Fighters

The growth of a strong set of champions for positive change was a major factor with these forming a strategic alliance.

These were then brought together in a multi-focus strategy that brought together those playing an internal game, within systems involving civil servants and elected officials (eg NAO, All Party Parliamentary Group on Dementia), those playing the external game (AS, mass demonstrations, focus on inequity of drug care in the press), and those playing the political game (increasing prominence in manifestos, building tripartite consensus the competition for who would do most).

Developing the Strategy

Making dementia a priority is only the first stage. There is then a need to develop what will go into the policy. How does one develop a national strategy for an illness that is so common, and where care can be provided by any combination of health services, social services, family and

friends, and the third sector? A further challenge is to deal with the fact that there are potential major problems at all stages in the complex care pathway.

From the start it was decided that the strategy should be designed to address the needs of all people with dementia, no matter of what type, age, ethnic origin or social status. A second important primary decision was to enter into as full a consultation as possible. An External Reference Group (ERG) was convened and chaired independently of the Department of Health by the Chief Executive of the UK Alzheimer's Society. A further strength was that the many reports over the years that had identified flaws in the system meant that there was a consensus as the areas needing attention from the start. So with the announcement made by ministers that dementia was to be a national priority it was stated that there would be a one year process to develop a national dementia strategy and implementation plan. The overall structure developed as a framework for this work stood up well in the development process. It was structured along three themes:

- 1. Improving public and professional attitudes and understanding of dementia**
- 2. Early diagnosis and intervention for all**
- 3. Good quality care and support at all stages from diagnosis through to the end of life**

Three ERG sub-groups worked on these themes generating a comprehensive report on improving dementia care which informed but did not determine the development of the strategy.

The development included two waves of formal external consultation organised jointly by the Department of Health and the Alzheimer's Society. The first, completed prior to developing the consultation document, involved a nationwide listening and engagement exercise where more than 3,000 people were able to contribute to and engage with developing the Strategy. The Alzheimer's Society also ran similar events especially for people with dementia and carers and distributed questionnaires, both through the Society's branches and online. Feedback from all these sources was reviewed to ensure that all views were captured.

A consultation document containing draft proposals was then generated by a DH strategy working group co-chaired by a senior social services leader and a senior dementia specialist from a health background (DH, 2008). This emphasised the need for joint and integrative approaches throughout. In the second phase, between July and September 2008, DH held a formal public consultation exercise on the draft proposals for the strategy, receiving over 600 written responses from individuals including those with dementia and their carers, and a wide range of professional and other stakeholder groups. These responses were analysed and informed the development of the final strategy. In addition 53 regional consultation events were held; over 4,000 individuals attended these meetings. Meetings covered the whole country including rural and urban areas, again specific groups were targeted with to ensure the views of diverse populations had been included in the development of the strategy such as: people with dementia themselves, people with learning disabilities, people from minority ethnic groups, and older people in prisons and remote and island communities. Officials from DH attended all these meetings as well as other dementia-related conferences and meetings across the country to publicise the consultation and gather feedback.

This process is clearly time-consuming and labour intensive so why bother? The answer to this is that **the inclusiveness and comprehensiveness of the development and consultation process for**

such a strategy lends it both validity and power when moving towards into implementation.
There is power in its provenance.

The National Dementia Strategy

Finally, the National Dementia Strategy was published in February 2009 (DH, 2009). The 17 interlinked objectives of the final strategy are presented in appendix 1 along with the summary paragraphs used in the strategy. It presents a comprehensive critical analysis of the current systems of providing health and social care for people with dementia and their carers. The objectives are not in order of priority but according to the narrative of the strategy which is based on a notional pathway through care:

Implementation

It would be all too easy to believe with the formulation of a strategy that the work is done. However nothing is achieved for people with dementia and their carers without implementation. This is a profound challenge at a time of budgetary restriction, a policy of increasing localism in decision making, and profound system change. However, not to act would waste the opportunities afforded by the delivery of a national strategy.

Each element of the NDS requires operationalisation in order to deliver the objective. The systems therefore need to be put in place to work out exactly how each can be achieved. As an example of this one of the issues identified as needing particular attention was the use of antipsychotic drugs for people with dementia. In the NDS this issue was included in the care home objective (Objective 11). This was acknowledged as such a priority that the Minister commissioned a review and the formulation of an action plan to run alongside the development of the NDS. This was completed and published in November 2009 (Banerjee, 2009) and the summary recommendations are presented below in Appendix 1. Following an investigation by Panorama, the Minister committed to an accelerated timescale for implementation of all recommendations.

There is movement, but it is only achieved and sustained by constantly re-applying the principles that got us to where we are modified for the new structures and the new orthodoxies and levers for change that arise:

- Dementia was included in the NHS Operating Framework for the first time in 2008/9 - “providing people with dementia and their carers the best life possible is a growing challenge, and is one that is becoming increasingly costly for the NHS. Research shows that early intervention in cases of dementia is cost-effective and can improve quality of life for people with dementia and their families. The Department will shortly be publishing details of the clinical and economic case for investing in services for early identification and intervention in dementia, which PCTs will want to consider when developing local services”
- It was included again in 2009/10 with detailed reference to the need to implement the NDS.
- Following the change in government dementia was one of only two new specific priorities signalled in the Revision to the Operating Framework for the NHS in England 2010/11 – “During the recent sign-off of SHAs plans, two areas stood out as not being given sufficient emphasis. The first is ensuring that military veterans receive appropriate treatment... The second area is dementia. NHS organisations should be working with partners on implementing the National Dementia Strategy. People with dementia and their families need information that helps them understand their local services, and the level of quality and outcomes that they can expect. PCTs and their partners should

publish how they are implementing the National Dementia Strategy to increase local accountability for prioritisation.”

- The identification and promotion of four priority areas for service development was made in “Quality outcomes for people with dementia: building on the work of the National Dementia Strategy” (DH, 2010)
- DH Commissioning packs have been developed and were published in 2011 to help commissioners get the right services for dementia, one of only three areas to have such an approach endorsed.

Drivers of success

1. Deriving clear, simple messages from the complexity
2. Professional approach to advocacy – the facts, the faces, the fighters
3. Clearly communicating the value of action (perceived benefit [hi]– perceived cost[lo])
4. Goal clarity – to develop a NDS, to implement...
5. Singularity of purpose – all players asking for the same thing
6. Specific rather than generic approaches – ageing has no face, dementia does
7. Strategy – play the internal, the external and the political games simultaneously
8. Helped by an international approach – external validation

ONE SIZE FAILS ALL – DEMENTIA, AGE DISCRIMINATION AND SPECIALIST OLDER PEOPLE’S MENTAL HEALTH SERVICES

One important element of good quality care for people with dementia is specialist older people’s mental health services. Here we will consider the question of what such services should do and problems in their provision including the role of age discrimination in generating the current state of service provision. The disparity in terms of quality and quantity of care provided for older people with mental disorders including dementia compared with that provided for adults of working age has led some, more or less benignly, to advocate that services for older people should be closed and there should be a single service for adults of all ages, since the presence of an age-defined service is age discrimination. In this chapter we will explore how and why such an approach might result in decreased service quality, decreased patient safety and decreased quality care.

What does good look like?

So what does good quality specialist mental health care for older adults look like? A simplistic reading of the situation in the context of the need to provide services that do not discriminate on the basis of age, might suggest that there should be a single service for all adults with mental disorder, or a single service for all adults with functional disorder and a separate dementia service. However, with a closer consideration of the clinical situation it becomes clear that there are systematic differences between the needs of older people and those of working age and that a specific service response is needed. On balance, there appears to be no better case for combining services for working age adults (be they functional or organic) with those for older adults than there are for combining services for working age adults with those for children.

Age discrimination in service commissioning

Age discrimination is addressed in the NHS Constitution whose first principle is “the NHS provides comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief”, and further that the NHS “has a wider duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population”. This is a fair description of the current state of specialist mental health services for older adults. The Equality Bill will outlaw age discrimination in all health and care services

There can be no doubt that there is age discrimination in the development, commissioning and provision of mental health services. The Healthcare Commission report *Older people’s mental health services: a national study* published in 2009, found that older people’s services were falling behind those for adults, with clear evidence of age discrimination in access to services, a lack of age appropriateness and lack of specialist input. Recommendations included suggesting that commissioners and providers assess all services for discrimination in access and deal with this. They were clear that this could not be achieved by simply providing access to services designed for younger adults. These are complex systems and simple answers may generate more discrimination and lower quality for older people rather than addressing these important issues.

A ‘one size fits all ages’ approach is more likely to increase age discrimination than it is to address it. This is because age here is a proxy for a different set of needs and therefore skills. The aim of the age equality agenda is to generate services of equivalently good quality for people of all ages. The nature of risk and need in older people with mental disorders means that, in order to provide services that are of equivalent quality to those available to adults of working age, specific provision needs to be made in terms of these different needs and skills. Delivering equivalent

quality of care is therefore likely to require enhancing current older people's mental health teams to have higher levels of functionality in terms of the capacity for assertive outreach, for example.

Why consider older adults separately from adults of working age?

The implications for our health and social care systems of population ageing are well articulated in the National Service Framework for Older People and form a major part of the rationale for the development of such age specific policy by DH and across government. We live at a time of worldwide population ageing and this has generated concerns about the ability of social systems and health care services to meet the needs of older people (WHO 1991; Organisation for Economic Co-operation and Development 1988). This is as active an issue in the developing world where countries are projected to experience a massive increase in the numbers of older people both in relative and absolute terms (Kalache 1991; Prince 1997; Ferri et al 2007), as it is in the developed world. The demographic projections in the UK, as in much of the developed world, are for an increase in the oldest old (those over 75 and those over 85) who have the highest levels of physical and psychiatric morbidity and therefore the greatest need. Particular concern has been focused in the developed world on the funding of long term care for the elderly, with dementia being a major determinant of need for this type of care.

In terms of service activity in psychiatry, older people are an important group. People over the age of 65 make up around a third of all mental health activity in the UK in terms of admissions, readmissions and community contacts (Philpot and Banerjee, 1998). However the profile of disorder and needs does differ from that in younger age groups. The challenges presented by dementia and co-morbid physical illness and disability require particular professional skills and services need to be able to deal with the complex mix of social, psychological, physical and biological factors found in the elderly mentally ill.

Old age psychiatry was developed within the UK health and social care system for two main reasons.

- The needs and risks presented by older people with mental disorder systematically differ from those presented by adults of working age. So a different set of skills is needed in the multidisciplinary teams charged with their care and a differentiated service response needed to meet these needs.
- It was clear that undifferentiated adult psychiatry services provided a poor quality service for those older adults that came under their remit in terms of diagnosis and management.

Different needs and risks

The special needs of the elderly include:

- a pattern of multiple pathology;
- complex co-morbidity of physical and mental health with social care needs;
- different patterns of social care and family support;
- the particular challenge of mental disorder in care homes; and
- dementia.

These were identified as requiring specialist training and multidisciplinary working with effective joint working with carers, primary health care, geriatric medicine and social services (Arie 1971; Royal College of Psychiatrists and British Geriatric Society 1979; Wertheimer 1997).

Development from undifferentiated services

Moves to develop specialist older people's mental health services out of undifferentiated adult psychiatry started in the late 1960s and by the mid-1990s there was a nationwide network of such services, albeit a network that had major variation in terms of resource available. These services were mostly staffed by full time consultants in old age psychiatry with community teams and wards dedicated to working with older people specifically (Lindsay and Banerjee 1992). As a discipline it defined itself from the first as having a primary community focus, insisting on the importance of home-based assessment and care (Arie and Issacs 1978). More recently, the World Health Organisation (WHO) consensus statement on psychiatry for the elderly has affirmed that assessments should be carried out in the patient's home (Wertheimer 1997). Unlike many principles, these appear to be the reality of clinical practice in old age psychiatry, with nine out of ten referrals seen at home rather than in out-patient clinics (Wattis *et al* 1981). However its development and differentiation has been based not only on ideology and the specific unmet needs of the elderly but also on a practical need to overcome institutional age-related prejudice within psychiatry (Murphy and Banerjee 1993).

Policy development for older people with mental disorder

The National service framework for mental health was explicitly targeted at working age adults, the validity of this decision can be debated but it was decided that general principles and specific services for working age adults should be addressed by the mental health NSF and specialist older people's mental health services by the older people's NSF. Here we need to consider some of the consequences in that problems for older people mental health services have become clear with the successes of the mental health NSF. The mental health NSF resulted in major investment and subsequent quality improvement of in-patient and community mental health services for working age adults. Across the country, it has become evident that these developments and improvements have not been matched by similar development or investment in older people's mental health services, which have in a sense been "left behind". This differential investment by commissioners, widening discrimination, was an unforeseen and unwanted consequence of the success of the mental health NSF.

The national service framework for older people (NSFOP) was a success in terms of embedding its generic goals of the need for dignity and respect to be at the heart of the National Health Service's response to older people. The specific clinical areas that it identified as needing particular attention have also been acknowledged to be correct and these include mental disorder in later life. However, due to the particular nature of the NSFOP's implementation, it has been necessary for there to be further policy development in order to achieve quality improvement in these specific areas. To date these include the development of the National Stroke Strategy and the National Dementia Strategy.

In 2005 DH through the Care Services Improvement Partnership published the good practice guide *Everybody's Business: integrated mental health services for older people*. This stated that services should deliver:

- non-discriminatory mental health and care services available on the basis of need, not age;
- holistic, person centred older people's health and care services which address mental as well as physical health needs.

The National Dementia Strategy on specialist older people's mental health services

The National Dementia Strategy clearly covers services for dementia outside specialist older people's mental health services. As with mental health care in general, dementia care is an issue for the health and social care system as a whole, rather than simply being the responsibility of

specialist older people's mental health services. However the interface with older people's mental health services is one of particular importance.

The consultation exercise for the National Dementia Strategy revealed strong concern from multiple sources about the future of specialist older people's mental health services and how they might be affected by the dementia strategy. In particular concerns were raised that this strategy might mean that there would be a push for the division of specialist older people's mental health services into organic and functional elements.

The National Dementia Strategy identified that specialist older people's mental health services are a vital component part of service provision for people with dementia. It concluded that, in order to work well for dementia, this requires strong, well-resourced and effective specialist older people's mental health teams. Finally it suggested that these teams needed to continue to have a role that extends beyond dementia, to include responsibility for older adults with schizophrenia, depression and mania so that they have the capacity and skills to provide the range of care needed for people with dementia. This was made on the basis that the separation of 'organic' and 'functional' disorders is essentially a false dichotomy for specialist mental health service provision, and one that is likely to disadvantage people with dementia with complex needs and their family carers. Specialist mental health services are needed that can deliver good-quality care that is attuned to the specific needs of older people. The natural history of dementia means that a substantial proportion of those affected will develop challenging behaviour, including symptoms such as depression, hallucinations and delusions. These are likely to require care from specialist older people's mental health services. For the system as a whole to work for people with dementia and their carers, these services need to be effective and available. This means services that work for older people with both functional and organic disorders and therefore a mixture of both.

Eliminating age discrimination in mental health service provision

As noted above there can be no doubt that there is age discrimination in the development and provision of mental health services.

There is a need to think very carefully through the options for action in response to age discrimination in order to ensure that we can be clear about the consequences of actions and to make sure that these result in the best quality outcomes for older people with mental disorder and their family carers. Accepting that age in itself is no marker of the need for a specific service and that services should be provided on the basis of need, proposals have been made to "open" working adult services to older adults either creating a single undifferentiated service for all adults or an undifferentiated service for adults with functional disorder and a separate service for people with dementia.

Such service change is often offered benignly in an acknowledgement of differential investment and growth and an attempt to:

- remove discrimination on the basis of age; and
- enable older people to have access to the services available for working age adults such as assertive outreach teams.

There are also other potential motivations for generating undifferentiated or dementia-only services that are worth articulating here in order to identify potential flaws in the reasoning. These include:

Motivation	Potential flaws
Cost containment or minimization	Combining services to save money. Cost saving should not be the reason for closing specialist older people’s mental health services and cost saving should not be presented as service improvement, especially since quality is likely to decrease for older people.
Convenience	Combining services for administrative simplicity. This should not be a driver for the amalgamation of services.
A sense of neatness	Splitting into functional and organic services appears neat and sensible. This ignores real clinical overlap both between disorder and in the skill set needed to manage the conditions in later life.
Implementing the dementia strategy	The creation of dementia-only specialist mental health services is the opposite of what is set out in the National Dementia Strategy.
Improving dementia care	There is no room for improving the quality of dementia care at the expense of older adults with other mental disorder.
Removing age discrimination by being “age blind”	There is ample evidence that adopting a position where one is “blind” to discrimination will only entrench that discrimination.

Opening working age adult services to older people - one size does not fit all

There are two main flaws in opening existing working age adult services. The first is that these services (be they general community mental health teams, assertive outreach, crisis resolution and home treatment teams) have been designed and have developed to understand and meet the needs of working age adults with severe mental illness. This will result in what Age Concern (2009) has termed “indirect age discrimination”, this is an “apparently neutral practice that disadvantages people of a certain age, eg designing services around the needs of young people without taking older people’s needs into account”. As discussed above, the needs of the two age groups are significantly different and it may not be possible to meet them in the same place with the same staff group. This is as true for the majority of older people with functional severe mental illness as well as those with organic disorder. It is striking that where services have opened their doors to older people how very few older people are taken on by these teams. However, there are a small group of older people with severe mental disorder who have needs that are indistinguishable from those of adults of working age and these may well be well served by these services and should not be denied them.

The second flaw is that the team may well not have the skills needed to assess, understand need, and plan and deliver effective care for older people with severe mental illness. This is because there are systematic differences in terms of complexity and co-morbidity which means that a different skill set is needed by staff of all professions in these teams. Skills developed with and for working age adults will often fail older people with similar disorders. The CSIP age equality guidance note states: “an ageing population has particular needs and it is essential that care is aimed at those who most need it... The mental health needs of older people are often multi-factorial and frequently complicated by failing physical health. This complexity requires the skills of specialist practitioners... Specialist mental health services for this group should be the bedrock on which other services can rely for clinical advice, support and practical help”. This is not simply a matter of training, it also involves attitudes and orientation.

Is an older adults service necessarily discriminatory in terms of age?

The short answer to this question is “no”. The slightly longer answer is “no, and not providing an older adults service is highly likely to result in care that is discriminatory on the basis of age”. The problem here is largely one of language.

The basic principle must be that services should be provided on the basis of need not age. However age is a reasonable marker of different need especially in mental health where the majority of incident cases of serious mental illness are in the 20-45 year age group, with a second peak from age 65 onwards with a second tranche of incident cases including those with dementia. There is a need for agreements between working age adults and older adult services that acknowledge that age is a guide rather than an absolute marker of service need. Such agreements have been reached in the majority of mental health trusts and common features include:

- Those that grow old with enduring mental health problems should stay under the care of the working age adult service they are familiar with unless their needs would be better met by the older people’s service
- Those with first episodes of mental illness after the age of 65 will be seen in the first instance by the older people’s service
- Those with first episodes of mental illness before the age of 65 will be seen in the first instance by the working age adult service
- Those with dementia of any age will be seen by the older people’s service
- Referrals of 'graduate' patients who are over the age of 65 who need continuing psychiatric input and who may have a specific need for specialist older people’s psychiatric services will be assessed and taken over, this will most commonly be because of physical frailty, co-morbid severe complex medical disorder, or the advent of a progressive dementia. In addition the older person’s service will receive referrals of patients under the age of 65 whose needs would be better met their services for the same reasons.
- Older people whose primary need is for specialist services such as substance misuse services or forensic mental health care will not be denied access and care from such services on the basis of age
- Where patients would benefit from joint working this should be provided
- The mechanism for resolution of dispute where agreement is not reached lies ultimately with the Trust Medical Director as an issue of clinical governance.

Such a system is not discriminating on the basis of age but is using age as a marker of difference in need so that different services are needed to provide services of equal quality to those with different needs.

Addressing age discrimination by providing equal quality of care

So the ‘one size fits all ages’ approach is more likely to increase age discrimination than it was to address it. This is because age here is a useful proxy for a different set of needs and therefore skills. The aim of the age equality agenda is to generate services of equivalent good quality for people of all age. Delivering equivalent quality of care is therefore likely to require enhancing current older people’s mental health teams to have higher levels of functionality in terms of the capacity for assertive outreach, for example. This would benefit those with dementia as well as those older people with functional disorder. In summary, the nature of risk and need in older people with mental disorders means that, in order to provide services that are of equivalent quality to those available to adults of working age, specific provision needs to be made in terms of specialist community mental health teams and inpatient services for older people with mental disorder.

Multi-functional community teams for mental health in older adults

The focus of these teams should be on the “serious mental illness” element of older people’s mental health dealing with urgent and complex disorders providing assessment and care in the community for older people with functional and organic disorders. The role of the memory services is a complementary one of early intervention and harm prevention in dementia and needs to be provided in a separate team. Delivering equivalent quality of care to that provided by community mental health services for working age adults is also likely to require enhancing current older people’s mental health teams to have higher levels of functionality in terms of the capacity for assertive outreach, for example. This would benefit those with dementia as well as those older people with functional disorder.

Liaison services in general hospitals

Up to 70% of acute hospital beds are currently occupied by older people and up to a half of these may be people with cognitive impairment, including those with dementia and delirium. Levels of depression in general hospital wards are also high (around 30%) and interfere with treatment and rehabilitation. The majority of these patients are not known to specialist mental health services, and are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia and depression in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation. This impact is not widely appreciated by clinicians, managers and commissioners. The NAO has estimated the excess cost of dementia to be more than £6 million per year in an average general hospital.

There are marked deficits in the knowledge and skills of general hospital staff who care for older people with mental disorder. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered and it can lead to under-recognition of delirium, dementia, and depression. Poor care can lead to malnutrition and dehydration for people with dementia, an outcome highlighted in the Age Concern England report *Hungry to be Heard*. The National Dementia Strategy presents three ways to deliver improvement:

- the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia care in the hospital;
- the development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician; and
- commissioning specialist liaison older people’s mental health teams to work in general hospitals.

Here we will focus on the commissioning of specialist liaison older people’s mental health teams working in general hospitals. They are advocated by the NICE/SCIE guideline on dementia services and can provide rapid high-quality specialist assessment and input into care planning for those with all possible mental health needs admitted to general hospitals, including input into on-going care and discharge planning. They will generally consist of a multidisciplinary team of three to four members of staff (part-time consultant, staff grade doctor, nurse and psychologist/therapist) with administrative support and a base in the general hospital. They can cover the whole range of mental health problems in older adults, not just dementia, but are likely to be of major value to people with dementia.

These teams could work closely with the designated general hospital lead to build skills and improve care through the hospital. They need to have good links with the social work assessment

teams based in or linked to the hospital. They are already provided in some but by no means all hospitals and there is major variation in composition and quality of the services provided across the country. Hitherto investment in mental health liaison services has focused on acute assessments in accident and emergency departments and is often focused on self-harm and acute psychosis in adults of working age rather than older people on the wards. There is also a clear need for specialist older people's mental health liaison services to be commissioned by PCTs to work on the wards with skills in the diagnosis and management of dementia and other mental disorder in later life.

Specialist dementia care services into care homes – looked after adults, the next battleground for quality

One-third of people with dementia live in care homes and at over two-thirds of all people living in care homes have dementia and up to a half have depression. This state of affairs has not been planned for, either through commissioning services or through workforce planning. In the past thirty years the proportion of people with dementia in care homes has increased by two to three-fold. The severity and complexity of needs of those admitted to care homes has also increased without changes in the ways that medical care is provided to homes. It is striking that while people in care homes, by definition, have the most severe and complex health problems in society, that they receive less specialist community health services than those living at home. Equally as these health problems have grown there has been no increase in primary care skills and input into these homes. The need for workforce development in health and social care is profound, and training in this area is covered in the National Dementia Strategy. Compared to the energy and effort that society puts into “looked after children”, it is striking that so little resource is committed to these “looked after adults” who are amongst the most socially excluded and disadvantaged in the community.

There is no doubt that residential care may be the most appropriate and effective way of meeting the needs of someone with dementia. There are care homes that provide excellent care paying close attention to leadership and staff management, staff training and development, and person-centred care planning. They can also provide a physical environment that enables people with dementia to move around the home safely and an active social environment with purposeful activities that relate to individual preferences. However, evidence from the Alzheimer's Society's *Home from Home* report and other sources show that in many homes, residents have little to do and there is immense social poverty with the typical person in a care home having just two minutes interaction with staff or other residents over a six-hour period of observation (excluding time spent on care tasks). The mental health needs of people living in care homes are extensive and generally not well met. Behavioural disturbance in dementia in these settings is both very common and a cause of stress to residents and staff. It is striking that there is very little in the way of active non-pharmacological management of these problems in care homes, despite accumulating evidence of the effectiveness of old age psychiatric intervention. Current input from mental health services is generally on an ad-hoc basis or reactive with referrals at times of crisis.

An issue of particular concern is the use of anti-psychotic medication in care homes for the management of behavioural and psychological symptoms in those residents with dementia. Those who have criticised current practice include the Parliamentary Accounts Committee, the Alzheimer's Society, the National Dementia Strategy and the All-Party Parliamentary Group on Dementia. It appears that there are particular risks that are serious and negative in the use of anti-psychotic medications for people with dementia, including increased mortality and stroke. There is accumulating evidence that in care homes they are initiated too freely, they are not

reviewed appropriately following initiation, and they are not withdrawn as quickly as they could be. Improving the quality of care in care homes requires these issues to be addressed effectively.

In the course of developing the National Dementia Strategy, one means suggested to address these problems has been the commissioning of a system of regular specialist mental health assessment following admission, and regular specialist review for this vulnerable population. This would enhance the quality of care by providing a regular forum for discussion between nursing staff, GPs and specialist older people's mental health teams to identify and manage the mental health problems of care home residents. Any intervention would need to be in partnership with the GPs responsible for care within care homes. In this system the quality of mental health care for residents in care homes could be improved by:

- specialist assessment of mental health needs following all admissions;
- regular six-monthly mental health reviews of residents in conjunction with the GP and nursing home staff;
- providing access to specialist advice for problems arising between reviews to prevent problems by means of a regular pattern of visiting;
- the formulation and deployment of non-pharmacological management strategies for behavioural disorder in dementia, so avoiding the initiation of anti-psychotic medication;
- specialist input into decision making concerning the initiation, review and cessation of anti-psychotic medication for people with dementia;
- rapid specialist review of all those with dementia initiated on anti-psychotic medication;
- rapid specialist response to problems as they occur within homes; and
- assessment of the residential care provided and the potential for improvement to create a more therapeutic environment.

Commissioners could achieve this by commissioning an extension of the existing role of the old age community mental health teams building on existing capacity, rather than by setting up a separate service. Joint commissioning of in-reach services from other professionals, such as community pharmacists, community dentists, arts therapists and geriatricians, could also improve support to care homes and enhance their environment.

In-patient care for older people with mental disorder

Sometimes older people with dementia and other mental health problems due to the nature and severity of their illness or risk to themselves or others will require a period of in-patient care. There are questions similar to those posed by the provision of community mental health care above which need to be answered in terms of how good quality, safe, in-patient care can be provided for older people that is not discriminatory on the basis of age. Most mental health Trusts will have specialist old age psychiatric wards that are staffed by specialist nurses and medical staff working as part of a multi-disciplinary team. Very few cases are admitted directly to such wards in that most people are assessed and managed in the community in the first instance and admitted only when there is absolutely no alternative.

In almost all areas there has been a decrease in the numbers of such acute assessment beds and the numbers are smaller than the numbers of general adult wards. In many units there will be only a single older people's mental health ward. There are three issues that are of particular concern at this time:

- The value of separating organic patients from functional patients

- The need for a specialist functional ward for older people
- The value of separating male from female patients

There is clinical heterogeneity in whether “organic” patients are cared for in a separate ward than “functional” patients. Such a division is attempted in some units but not others. There is no clear consensus about whether it is better to have segregated or mixed wards and this can cause confusion for commissioners and for Trust management. The argument for mixed wards are that many people who are admitted have complex mixed disorders or uncertain diagnoses which is why they are admitted. Also running two wards can be more expensive than running a mixed unit and “organic” wards can become gloomy places taking on the negative attributes of some care homes. Advocates of separation would report that many people complain that they do not like being on a ward with people with dementia. However it is often people with dementia who are lacking in insight that make such comments and they would be on the dementia-only ward in a segregated system. Also the individuals they complain about may well be people with psychosis or depression whose behaviour is disturbed. There is a need for the faculty of old age psychiatry to produce definitive guidance in this area.

One possible consequence of separating organic from functional wards for older people is that the older people’s functional ward is closed and that older adults with functional disorders are admitted to the same wards as working age adults. This can be seen as a cost saving exercise or the logical extension of abandoning a missed system. The problems with this are that older people often find wards filled with adults of working age with serious mental illness very intimidating environments. Also the same issues with respect to the need for a different skill set in order to deliver good quality care applies in this case. Older people have a different pattern of risk and need and so may not meet criteria for admission or may be discharged more quickly than would be best. There are few examples of this approach working well but again there is a need for the faculty of old age psychiatry to produce definitive guidance in this area.

Finally gender separation at a ward level is seen as a good thing in working age adult services and generally in the health services. Why might this be a problem for older people with mental problems? The answer is that there is often only a single ward in a particular area. If there is gender separation then it may be that the male or the female ward will be in a neighbouring PCT, thus increasing markedly the distance that visitors (who are often old and frail themselves) need to travel. Older people have long stay lengths and this can prove problematic. This is not such a problem for working age services where there are usually multiple wards in a single area allowing such separation. The issues become amplified if one separates on the basis of diagnosis and well as gender. One way ahead is for older people’s mental health wards to be built so that everyone has their own bedroom with their own en suite bathing facilities. This enables everybody to have their own space and avoids the need for separation by gender or diagnosis.

Appendix 1

Objective 1: Improving public and professional awareness and understanding of dementia.

Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

Objective 3: Good-quality information for those with diagnosed dementia and their carers.

Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

Objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

Objective 5: Development of structured peer support and learning networks. The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

Objective 6: Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

Objective 7: Implementing the Carers' Strategy. Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

Objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

Objective 13: An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

Objective 14: A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy.

Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers. Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

Objective 16: A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.

Objective 17: Effective national and regional support for implementation of the Strategy. Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

Appendix 2 Recommendations to deliver improvements in the use of antipsychotic medication for people with dementia

Recommendation 1: Reducing the use of antipsychotic drugs for people with dementia and assuring good practice when they are needed should be made a clinical governance priority across the NHS. Using their existing clinical governance structures, Medical Directors (or their equivalent) in all primary care trusts, all mental health trusts and all acute trusts should review their level of risk in this area and ensure that systems and services are put in place to ensure good practice in the initiation, maintenance and cessation of these drugs for people with dementia.

Recommendation 2: National leadership for reducing the level of prescription of antipsychotic medication for people with dementia should be provided by the National Clinical Director for Dementia, working with local and national services. He or she should report on a six-monthly basis to the Minister of State for Care Services on progress against the recommendations in this review.

Recommendation 3: The National Clinical Director for Dementia should develop, with national and local clinical audit structures and leads, an audit to generate data on the use of antipsychotic medication for people with dementia in each primary care trust in England. This audit should be completed as soon as possible following the publication of this report, generating baseline data across England. It should be repeated one, two and three years later to gauge progress.

Recommendation 4: People with dementia should receive antipsychotic medication only when they really need it. To achieve this, there is a need for clear, realistic but ambitious goals to be agreed for the reduction of the use of antipsychotics for people with dementia. Explicit goals for the size and speed of this reduction in the use of antipsychotics in dementia, and improvement in their use where needed, should be agreed and published locally following the completion of the baseline audit. These goals should be reviewed yearly at primary care trust, regional and national level, with information published yearly on progress towards them at each level.

Recommendation 5: There is a need for further research to be completed, including work assessing the clinical and cost effectiveness of non-pharmacological methods of treating behavioural problems in dementia and of other pharmacological approaches as an alternative to antipsychotic medication. The National Institute for Health Research and the Medical Research Council should work to develop programmes of work in this area.

Recommendation 6: The Royal Colleges of General Practitioners, Psychiatrists, Nursing and Physicians should develop a curriculum for the development of appropriate skills for GPs and others working in care homes, to equip them for their role in the management of the complexity, co-morbidity and severity of mental and physical disorder in those now residing in care homes. This should be available as part of continuing professional development.

Recommendation 7: There is a need to develop a curriculum for the development of appropriate skills for care home staff in the non-pharmacological treatment of behavioural disorder in dementia, including the deployment of specific therapies with positive impact. Senior staff in care homes should have these skills and the ability to transfer them to other staff members in care homes. A national vocational qualification in dementia care should be developed for those working with people with dementia.

Recommendation 8: Each primary care trust should commission from local specialist older people’s mental health services an in-reach service that supports primary care in its work in care homes. This extension of service needs the capacity to work routinely in all care homes where there may be people with dementia. They may be aided by regular pharmacist input into homes. This is a core recommendation of this report and it requires new capacity to be commissioned by primary care trusts in order that the other recommendations can be met.

Recommendation 9: The Care Quality Commission should consider using rates of prescription of antipsychotic medication for people with dementia, adherence to good practice guidelines, the availability of skills in non-pharmacological management of behavioural and psychological symptoms in dementia and the establishment of care home in-reach from specialist mental health services as markers of the quality of care provided by care homes. These data should be available by analysis of local audit data and commissioning decisions.

Recommendation 10: The Improving Access to Psychological Therapies programme should ensure that resources are made available for the delivery of therapies to people with dementia and their carers. Information and support should be available to carers to give them the skills needed to spot behavioural problems quickly, to seek help early and to deploy elements of non-pharmacological care themselves in the home.

Recommendation 11: Specialist older people’s mental health services and GPs should meet in order to plan how to address the issue of people with dementia in their own homes who are on antipsychotic medication. Using practice and patient-level data from the completed audits on the use of these medications, they should agree how best to review and manage existing cases and how to ensure that future use follows best practice in terms of initiation, dose minimisation and cessation.

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