Transforming the quality of dementia care: Consultation on a national dementia strategy.

**June 2008**

RESPONSE TEMPLATE

Closing date for responses: 11 September 2008

Please send to: dementia.strategy@dh.gsi.gov.uk

Alternatively, they can be posted to:

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Before submitting your response to the Department, please make sure that it has been saved in a name that will make it easier for us to track. Many thanks.
Respondent Details (Please provide the details of a single point of co-ordination for your response)

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If you are replying on behalf of a group of respondents or a number of organisations, please complete the following information:

| Organisations represented within this response | ADASS and LGA |

Response details

| Date of response: | Closing date: 5pm on 11 September 2008 |

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Views are sought on the following:

Chapter 1 – Improved Awareness

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

We welcome the focus on raising awareness and promoting early diagnosis and agree this is important. It is important to ensure that as well as raising awareness of the symptoms, the tendency to downplay symptoms of dementia as a natural aspect of ageing is also addressed. The objectives will be challenging to achieve within the current budgets and service pressure. Older people particularly are dealing with high volumes of referrals and these will grow with raised awareness.

2. Is there anything that has been missed to help us improve public and professional awareness of dementia?

It is important to ensure that awareness of dementia is set into the context of raising awareness of mental illness in older people generally to ensure a coherent approach to its management can be established and maintained.

Training programmes need to have awareness of dementia and its impact on the lives of individuals and their families at the centre. It is important that they also focus on the contribution that people with dementia can make to the community and on the strategies that may help them do so.

Recruiting and retaining high quality staff is vital to the success of this strategy and the Government needs to ensure that sufficient resources are made available to realise this. Currently there is little incentive for staff to remain in this difficult and challenging area when better paid alternative employment is readily available and we should not as a matter of policy rely on the motivation and goodwill of those who do choose to remain. They should receive appropriate recognition for their contribution.

3. What can you or your organisation do to help implement the recommendations?

Local Authorities have a key role to play in the implementation of the recommendations and ADASS is committed to promoting awareness of dementia through communication with its members and the active promotion of best practice using our existing networks.

In particular through partnership working with colleagues in the Health Service we will seek to promote an integrated approach to treatment and social care by raising awareness of the need
to align the personalisation agenda within social care to that within the NHS. Such an approach will ensure the most efficient use of resources whilst at the same time offering a truly seamless service to people with dementia at whatever stage of the condition. Workforce development resources are crucial and should be focused on training staff in core competencies in dementia care. This includes a broader group of staff than those in health and social care, for example housing staff.

We will look at our communication strategy to ensure that we have the most appropriate vehicles in place to deliver key messages about dementia for both those with dementia and their families and carers in a creative and positive manner, to ensure that dementia is not seen as a life sentence but as a way of living life in a different way.

The personalisation agenda must take account of the particular needs of this group and will seek to ensure our members adopt an approach to the provision of care and support that maximises choice and control for people with dementia and their families and carers.

We can also raise awareness within local government of dementia as a strategic challenge to the wider public service and local authority functions, not just social care.

Thank you
Chapter 2 – Early diagnosis and intervention

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

We welcome the recommendations, in particular the emphasis on offering good quality diagnosis and intervention including early guidance and advice for all and the recognition of the vital need for good quality information for people with dementia and their families and carers. There needs to be greater clarity about recommendation 5, as to how continuous support and advice will be provided. Proper pathways and an integrated approach between social care and health will be vital to the delivery of this important recommendation.

2. Is there anything that has been missed to help enable early diagnosis and intervention?

Currently many local authorities are only able to assist people with either critical or substantial needs categories, which will not include the majority of people with mild dementia. Extending the reach of local authority provision to all those who are affected from this condition requires significant additional resources and further debate is required to determine how best these can be provided.

Early diagnosis and immediate care present a major challenge, which can only be met through a more flexible approach to performance measurement and delivery of support than the current system allows. In particular a specialist approach in areas such as reablement will be required and consideration needs to be given to how best this can be achieved and recognised.

3. Do you agree that the diagnosis of dementia should be made by a specialist?

Yes. It is important to public confidence that a diagnosis is reached by an appropriately qualified person who also has the appropriate skills to communicate it sensitively and to offer a range of support services and management programmes that can assist in maintaining function and quality of life for the person with dementia and their families and carers. It is important that this is done in a multi-disciplinary approach. There will always certainly be a higher demand for services to support people at home and sufficient investment from the NHS as well as social care will be needed.

4. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to a GP first?
It is important to ensure that GPs are aware of their patients’ medical history and current treatment and diagnosis. However, this requirement does not mean that they need be the only route into diagnosis and treatment and consideration needs to be given to developing robust systems that will allow people to access services, such as memory clinics, via routes within the community, while at the same time ensuring that individual GPs are aware of what is happening to their patients.

5. How would the dementia advisers be able to ensure continuity of care?

The advisers will need to be part of a multi disciplinary service with excellent communication between all members of team. Dementia advisers will need high quality training to ensure that they have a detailed understanding of the needs of people with dementia and their families and have an excellent awareness of where services and support can be sourced within the community. Individual authorities will need to ensure they have excellent administrative and support arrangements in place to facilitate the process and enable continuity of care.

6. What can you or your organisation do to help implement the recommendations?

We recognise the importance of early diagnosis and intervention and will seek to ensure that our members adopt best practice in this area. In particular we will seek to promote and embed effective partnership working with colleagues in the NHS to ensure that local services are geared to providing the necessary infrastructure.

Within Social Care we will encourage our members to look at the skills base of their staff in this area to ensure that gaps in training and professional development can be addressed so that care staff at all levels will be able to recognise and refer service users who may exhibit symptoms of dementia and their families to appropriate diagnostic and support services.

Thank you
Chapter 3 – High-quality care and support

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

We welcome the recommendations. Recognition of the need for better quality care for people with dementia, whether in hospital or the community, is long overdue. Carers have highlighted the very real difficulties experienced by people with dementia when accessing acute health services and we welcome recommendations that will lead to improvements in this area. We would like to see a broader approach adopted in some areas, in particular with regard to recommendation 6, where there is a need to ensure that community hospitals managed by PCT providers are not excluded and that intermediate care be of sufficient length to allow persons with dementia to benefit from it. Improved home care services will be essential and they will need to be available for people with low level needs as well as those in the later stages of dementia. Experience currently is that there is less capacity to provide services at the lower level of need.

2. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?

The strategy should strengthen references to the role of housing and extra care housing, Telecare and telehealth, as important in enabling people to remain at home.

We welcome the proposal to introduce a registration regime for care homes offering services to people with dementia. To make this work effectively, CSCI and CQC inspection regimes will need to be aligned. In developing any such registration and inspection process care needs to be taken to ensure that smaller providers are not excluded from the regime as many people with dementia live in non-specialist care homes. It is also important that a registration regime does not promote over specialisation within the care home sector. We would wish to see all care homes demonstrably capable of providing services to people with dementia. Additional registration could, if not broadly based, result in a reduction in the supply of places with a subsequent adverse impact on those requiring a residential placement.

It is important for the Government to recognise that the operation of any such regime will require the commitment of sufficient resources. However there is likely to be an offsetting saving to public funds from early intervention and prevention. Local authorities alone will not be able to shoulder any additional financial burden.

The draft refers to at least 15 000 people under the age of 65 with dementia in England. This is likely to be an underestimate. Developing dementia at a younger age when a person may have dependent children, a job and financial commitments has wide reaching implications. Getting an accurate diagnosis can take a very long time with misdiagnosis of depression or stress being common. Once diagnosed there may be difficulties accessing dementia services that are often age specific and may not be equipped to meet the needs of younger people.

We would like to see the strategy include specific reference to the needs of people with young
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onset dementia including recommendations that Local Authorities and the NHS should plan for and commission services that will meet those needs

Reference should be made to day services which provide a range of support to people living at home and are provided by both local authority and voluntary independent sector.

3. What more could be done in acute care, home care and care homes?

The proposals in the consultation are very welcome, in particular the emphasis on providing meaningful and enjoyable activities for residents. In the context of the proposed registration regime this should be one of the key criteria for registration and the activities should encourage engagement, not just from the resident but, where possible, from their families and friends to help ensure that valuable social contact and circles of support are not lost when a person is admitted to residential care.

We understand that work is currently underway regarding the use of antipsychotic medication for people with dementia. The result of this work should be widely disseminated and reference made in the Strategy to the need for strict controls and regulations on the use of these medications in care homes.

4. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?

It is essential for the successful delivery of personal budgets to people with dementia that both the assessment process and support planning process and the associated forms and information are geared to the needs of these service users and that all staff providing help and support in this area have received appropriate training. Particular attention needs to be given to the outcome measures in individual support plans and the additional support required in developing these to ensure they are appropriate for the individual and their family or carers.

5. What can you or your organisation do to help implement the recommendations?

Joint commissioning of services is critically important to the success of this strategy. Joint strategic needs assessments in localities should inform joint commissioning plans, and world class commissioning guidance should strengthen the process. We will be suggesting that implementation should be supported through regional joint improvement partnerships. As the level of demand and need for dementia services is growing we would expect to see this reflected in LAA priorities and targets for improvement, supported by performance improvement funds.

We will seek to ensure that our members take a holistic approach to providing support to
people with dementia. It is not sufficient to provide high quality care services, our approach will stress the need to maintain independence and to provide appropriate support to people living with dementia to allow them to remain active in the community through the medium of personalisation and ultimately integration of provision between health and social care.

A multi-disciplinary approach will be required not just within Social Care but across Local Authorities to ensure that all areas of activity take full account of the needs of this group, whether it be planning and issues of accessibility to the built environment, or areas such as emergency response where there is a critical need to understand the particular challenges faced by people with dementia.

We will also seek to promote an approach that recognises the particular needs of people with dementia and their families in the provision of sensitive and appropriate end of life care, to ensure that their dignity is respected and as much choice and control as possible remains with the individual and their family.

Thank you
Chapter 4 – Delivering the National Dementia Strategy

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

We welcome the recommendations, in particular the recognition that clear information on delivery backed up by research and effective support for implementation is vital to its success.

2. Is there anything that has been missed to help us deliver the National Dementia Strategy?

Delivery requires appropriate resources and as Appendix 4 suggests, an additional £220million per year is needed to fund:

- Memory services (£95m)
- Extra support for existing community mental health team for older people (£70m)
- Enhancement of social services (£55m).

However, while some of this money can be found by reducing admissions to residential care, these figures do not take full account of the additional staffing that will be required to deliver this strategy nor do they recognise that for some areas which have a disproportionately high number of elderly residents, the financial burden on individual local authorities may be significantly higher. Additional financial support will be required from the Government.

3. What are your priorities for implementation? What can and should be done first?

At this stage it is unclear what if any additional money will be made available to support this strategy. Our approach has to recognise that there are finite resources and prioritise accordingly. This means that we need to use resources creatively to reconfigure services to ensure that we are able to offer support to those most in need of it, including self funders and those at an early stage of the condition who do not meet local authority eligibility criteria.

In particular we attach great importance to the prevention agenda which, effectively implemented, offers great benefit to the individual and to the local authority. We see this as the route to sustainable high quality provision in this hard pressed area.

It is important to ensure that the outcome of the current consultation on the long term future of social care and the CSCI review of Fair Access to Care Services adequately addresses the key recommendations in this strategy in relation to the position of people with long term conditions where needs fluctuate or function declines over a long period of time.
4. What should the timetable for implementation be?

There is much in this strategy that Local Authorities can and should be acting upon already and in many cases are doing so. For example the move to personalisation and the development of innovative services for older people and carers, such as telecare, development of outreach and support services, promotion of peer support and greater involvement of families and carers.

There is an urgent need to implement the personalisation agenda in the health service and we see this as a priority area. However without appropriate resources there will be a limit on what can be achieved.

5. What can you or your organisation do to help implement the recommendations?

We will actively use the existing mechanisms to ensure that this strategy remains firmly on the Government’s agenda, and will ensure that the concerns and the successes of our members are effectively communicated. We will work in partnership with all public bodies and service users and their representatives to ensure effective implementation and ongoing review.

6. Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups?

More consideration needs to be given around how to reach groups where traditional family networks tend to exclude outside support and where conditions such as dementia may not be either fully recognised or deemed to be culturally acceptable.

Thank you
ADASS and the LGA welcome the proposals put forward in this consultation and agree that they represent a sound way forward to raise the quality of dementia care. In our view there has been insufficient emphasis on dementia in national health strategy and Lord Darzi’s review and, given the impact of this condition upon the lives of people, their families and carers, and the growing numbers affected, a national, strategic approach is long overdue.

Dementia needs to become a higher priority for health and social care and spending priorities and the performance management regime need to reflect this. It is essential that adequate funding and resources are committed if the aims and objectives of the strategy are to be realised.

Most people with dementia live at home with support from their families and local government services. To improve the quality of that support and ensure that it reaches all those that need it, a significant increase in the capacity and volume of services will be required. This has serious implications for funding and targeting of resources. The DH workforce strategy should recognise the importance of developing the skills and competencies of the workforce in dementia care. Guidance on the use of the workforce development funding should prioritise this area.

We welcome the move to align dementia with the approach of *Putting People First*; extending personalisation, choice and control to people with dementia and their families is vital to preserving dignity and engendering the respect they have the right to expect. Transforming social care alone is not sufficient. Health care systems must also be radically changed to ensure that they offer real choice and maximum possible control to service users and appropriate support to their carers and/or families through the medium of individual budgets in Health. The concept of the expert patient must be made a reality through the medium of these budgets by allowing the patient to determine, in so far as is possible, what type of treatment they want and where they receive it. We would actively seek to promote alignment between personal budgets in social care and individual budgets for Health care to ensure that integrated self-directed care and support is available to all. The DH Implementation Plan should resource work at a national, regional and local level. There is value in regional networks to support and share good practice, and focused support for improvements.
Thank you