RESPONSE TO TRANSFORMING THE QUALITY OF DEMENTIA CARE: CONSULTATION ON A NATIONAL DEMENTIA STRATEGY

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INTRODUCTION

Whilst it is clear that parts of the draft strategy are inclusive, and improving social care and health services clearly need to be key priorities for this strategy, in key areas the focus is too narrow. The effect of this is to miss opportunities for achieving the strategy outcomes for some people with dementia - possibly more cost effectively - through housing sector services, and indeed those of other independent sector organisations.

This response considers the draft strategy from a housing sector perspective. It follows the order in the consultation document.

PURPOSE AND SCOPE OF THIS DOCUMENT

P13 pen-ultimate bullet point. Can you please define “third sector” and explicitly whether or not it includes non-statutory housing providers? Whilst my understanding is that the term includes housing associations, a straw poll of definitions at the ERG meeting on the 14th July ranged from “all non-statutory services” to “voluntary sector services but not private sector services.”

Suggested change: *Include a glossary of terms*

IMPROVING PUBLIC AND PROFESSIONAL AWARENESS OF DEMENTIA

Recommendation 1

Very good. Nothing to add.

Recommendation 2

This is the right outcome but the focus is too narrow. The focus on health and social care staff in this outcome is a serious missed opportunity for ensuring that other professionals who have significant contact with people with dementia have the necessary skills and competencies. These might include Extra Care Scheme managers, sheltered housing managers, Community Alarm staff, floating support workers etc.

This point seems to be recognised at the top of page 31, but the actions outlined in recommendation 1 for “public-facing employees” are inadequate for this group of professionals. If the wording of the outcome were to be changed as follows, housing would then be included, and the sector would be required to develop training and core competencies for those staff who provide services for people with dementia.

Suggested change. *Re-word recommendation 2 as follows:*

"All staff involved in the care and support of people with dementia to have the skills needed to provide the best-quality care and support in the roles and settings where they work.... etc"

The Summary Proposition for consultation on Recommendation 2 (p32) talks about core curriculum and training for "all those" who work with older people... which is excellent, but then refers to "care providers" when it would be more inclusive to say "service providers". (The first sentence is also rather confusing)

If housing sector staff had the necessary training and information, they could make a significant contribution to raising awareness and reducing stigma amongst the people they work with – for example groups of tenants in sheltered housing.

Suggested change: *Replace the term "care" provider with "service" provider in the Summary Proposition for Recommendation 2*

EARLY DIAGNOSIS AND INTERVENTION

Recommendations 3,4 &5

These seem to be the right outcomes. However, once again, in recommendation 4, the focus is too narrow, excluding information on housing and housing-related services. In Figure 3 showing the simplified care pathway for dementia, the "Collaborative care informed by diagnosis" oval could be "Collaborative care and support informed by diagnosis" and the oval should include a fifth arm, "housing and other third sector services" . If these are not included here, we will see the continuation of a situation where people with dementia and their carers lose out because navigators are unaware of options other than traditional health and social care.

Housing sector staff can make a significant contribution to providing information and supporting people both pre-and post-diagnosis, encouraging them to seek a diagnosis and signposting them in the right direction – provided they have the necessary training and information.

Suggested change: *Amend figure 3 to include the term "support" in the main oval, and add a fifth arm "housing and other third sector services"*

Also, diagnosis can sometimes be a long drawn out process. It would be better if good-quality information were available to all those suspected of having dementia.

Suggested change: *"People with suspected dementia and their carers to be provided with good-quality information on the illness and on services available – from pre-diagnosis onwards."*

There needs to be another recommendation. This may fall within the Early Intervention section or High Quality Care and Support. It goes beyond provision of information about housing and third sector options,

and relates to the independence-prolonging and preventative role that the provision of low level support services can play.

Such services may include a monitoring and checking service using assistive technology, other assistive technology devices, a visit from a Care and Repair agency if the house needs adapting, a floating support package, befriending by a voluntary organisation, a move to sheltered or extra care housing, or taking part in activities at retirement housing. The dementia care adviser and other professionals would need to have information on such services.

They are valuable both because they can enhance quality of life and independent living, but also because FACS eligibility thresholds have up until now precluded many people in the early stages of dementia from statutory sector services.

Suggested change: *Introduce another recommendation whose wording may be:*

" People who may have dementia and their carers should have access from an early stage to a wide range of low level support services such as those provided by the third sector to help prolong independent living and delay reliance on more intensive services"

HIGH QUALITY CARE AND SUPPORT

These recommendations and outcomes are good as far as they go. Unless the mechanisms for implementation are identified and applied they are merely aspirational.

This may be the appropriate section to include the previously mentioned additional recommendation on access to support services.

Paragraph 2 on page 43 points to the benefits of specialist home care. The same benefits are likely to apply to specialist housing for people with dementia, although research is needed into this. In addition, where home care is delivered in settings where housing staff also work, the better the latter's knowledge and skills base in meeting the needs of people with the dementia and their families, the more likely it is that the person with dementia will be supported effectively to continue living there. Here again, the importance of training in dementia for housing staff is clear.

Suggested change: *In answer to the second consultation question about what is missing, a sentence or two should be added about the role of housing staff - and the potential contribution of specialist housing - in ensuring co-ordinated, high-quality care and support for people with dementia.*

Recommendation 9

The idea of a "joint commissioning strategy for dementia" is most welcome – presumably at a local level. It is not clear what is envisaged by the phrase "comprehensive integrated pathway of care" , but once again, a range of services risk being overlooked through concentration on health and social care services, although mention of "access to supported housing that is inclusive of people with dementia" and "assistive technologies such as telecare" is to be welcomed. On page 53 under Recommendation 15 on "Effective Support for Implementation", there is a good paragraph on "new models of supported housing (such as extra care)...". It would be better for these points to be part of Recommendation 9 on a "joint commissioning

strategy for dementia" since including these new models as part of implementation makes more sense if they have first been part of the core recommendations. Voluntary sector support services, floating support funded by Supporting People and the work of home improvement agencies can work alongside more formal social and health care services to improve the safety and well-being of people with dementia and their carers. Third sector support and home improvement services should be added to the list under "A comprehensive home support service would provide:" on page 44.

Suggested change: *Add a paragraph on new models of supported housing such as extra care. Extend the list under "comprehensive home support service" to include voluntary sector support services, floating housing-related support services, and home improvement agencies.*

In order to implement this recommendation, it would be really good if each area covered by a Local Area Agreement were required to appoint a jointly funded (social care, mental health and housing at a minimum) dementia champion to co-ordinate information gathering for the JSNA, develop the key elements of the strategy with a dementia focused Local Strategic Partnership, and facilitate inter-sector working at all levels to implement the strategy.

Suggested change: *Add a requirement in the strategy for the appointment of a jointly funded dementia champion in each adult social care area.*

DELIVERING THE NATIONAL DEMENTIA STRATEGY

Once again, the outcomes identified in recommendations 13 to 15 seem sound as far as they go. Arguably baseline information on the "content and resources of dementia services" should include housing-related services for people with dementia - for example, the number and model of extra care schemes which target people with dementia.

Recommendation 14 regarding "research evidence and needs" should be broadened to cover research into the effectiveness of housing and support services for people with dementia, not only "cure and care" research.

Suggested change: *The strategy should make it clear that baseline information should not be restricted to health and social care services targeted at people with dementia, and research evidence and needs should be broadened to include the effectiveness of housing-related services.*

The Housing LIN is taking steps to facilitate identification of levers and incentives for implementing the housing sector contributions, but the sector needs to be clearly included in the strategy to give weight to such attempts.

In addition, in order to implement some aspects of the housing sector contribution, cross-sector measures need to include housing. It cannot be left to the housing sector alone. For example local older people's strategies, strategic needs assessments and local area agreements, inclusion of housing services in information for families with dementia, joint training opportunities, all require health and social care at all levels to recognise the role the housing sector can play and ensure the sector's inclusion.

Suggestion for Delivering the National Dementia Strategy: *The implementation plan coming out with the revised strategy needs to incorporate the housing sector where relevant, preferably explicitly or failing that, at least by the use of inclusive rather than exclusive terminology.*

CONCLUSION

It would not take much to broaden this strategy to include the housing and the third sector generally without in any way diluting the specific social and health care outcomes. This in turn would result in:

- a wider range of services to support people with dementia, spreading the costs more widely;
- more opportunities for self-determination and citizenship;
- collaboration and seamlessness extending beyond health and social care;
- and achievement of better outcomes in terms of prevention and prolonged independence;
- and possibly delivering savings to the economy .

Finally - the division of the draft strategy under three priority headings means that measures which could contribute to the outcome of improving the health and well-being of people with dementia and their carers, but fall outside those three strands, have been completely overlooked. These include:

- Planning and development: the design of housing and the wider environment with the needs of people with dementia in mind
- Public and environmental health: the contribution that warm, comfortable, safe and secure housing can make to physical and mental well-being of people with dementia