

Health and Care Bill - Second Reading – 14 July

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1. Summary

- While people with dementia are the majority user group of adult social care, people with dementia often have other health needs given ageing or other diagnoses. It is vital that NHS healthcare, and particularly the vision for integration which this Bill outlines, supports their wellbeing.
- The Bill's plan for integration is driven by NHS priorities and resources, not social care, meaning an opportunity missed for parity between the two.
- In the absence of a plan for social care reform, it is difficult to gauge how successful these plans for integration will be. We urgently need to see a plan for social care reform which goes beyond funding and enables people with dementia to live with meaning, purpose and connection.

2. Background

There are an estimated 850,000 people living with dementia in the UK, with this number set to rise to nearly 1.6 million by 2040.¹ Dementia is a progressive, long-term health condition with huge care costs attached. **It has been estimated that at least 70% of care home residents and over 60% of home care recipients are people with dementia.**²

The [Health and Care Bill](#) was announced in the Queen's Speech on 11th May and introduced on 6th July. It allows for the continued development of Integrated Care Systems (ICSs) in England, seeking to bring together health and social care. The ICSs will be obliged to set up a Board of NHS and local authority representatives (ICB), and wider Partnership (ICP) arrangements with potential for involvement from the voluntary sector.

While there is no meaningful treatment or cure for dementia available on the NHS, 90% of people with dementia have one or more co-morbidity³ which means that they often require NHS input to support their wellbeing, but receive the majority of their support from social care.

People with dementia are one of the primary groups who would benefit from greater integration between health and social care. Currently, too many receive uncoordinated, noncomplementary or insufficient health and social care.

3. Integration and social care reform

The Health and Care Bill seeks to integrate health and social care, which is welcome. However, this is approached from the perspective of NHS resource and priorities.

While the Bill largely drives and centres on NHS provision and use of NHS resources, this is a golden opportunity to treat social care providers and local authorities as an equal partner from the outset. Language that "NHSE must establish bodies called ICBs" risks NHSE being considered the 'lead' in ICBs that are intended to be (and should be) partnerships. Integration and collaboration will only succeed if there is greater parity between different parts of the system.

¹ Wittenberg, Raphael et al. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. 2019. Care Policy and Evaluation Centre, London School of Economics and Political Science. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf.

² Alzheimer's Society. Dementia UK: Update. 2014.

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf; <https://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf>.

³ J Browne et al (2016) Association of comorbidity and health service usage among patients with dementia https://research-information.bristol.ac.uk/files/120965391/e012546_full.pdf

In the absence of a plan for social care reform from Government, it is difficult to gauge how successful the integration project will be for people with dementia who draw on both health and social care support.

We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us. We need an urgent plan for social care that addresses key challenges around funding, the workforce and fair, equitable access to quality care for people with dementia and carers to make this vision a reality.

With regard to the social workforce in particular, we need the Government to recognise the importance of support for staff by working with staff and other stakeholders to develop and **publish a People Plan for social care, to pair with the NHS People Plan.** Such a plan must reflect the needs and aspirations of those who use social care in its proposals for improving staff skills, recruitment and retention.

4. Accountability and involvement

Alzheimer's Society believes **an essential component of integrating care and support for someone with dementia is to work in partnership with the person receiving that care and support, and those who care for them,** to understand what matters to them in their care.

The Bill does not speak to the vital issue of strengthening accountability to local people who draw on care and support. There is a missed opportunity to support greater transparency in decision making or enabling local people to challenge practice or decisions that affect their care or wellbeing. While the Bill proposes increased accountability to the Secretary of State, there is no equivalent strengthening of local and user accountability.

Similarly, there is a **missed opportunity within the Bill to involve VCSEs** (Voluntary Community Social Enterprise Sector) i.e. charities and voluntary organisations. VCSE should be considered as equal partners in decision making rather than an afterthought. **There should be a clear structure enabling VCSEs to be involved in decision making.** Integrated Care Boards will include nominated representatives of NHS Trusts, primary care providers and local authorities - a similar structure could provide nomination for representatives of the VCSE – and we should see standard involvement of VCSEs on Integrated Care Partnerships.

Alzheimer's Society **welcomes a new responsibility for CQC to understand and review the provision of social care in local systems to ensure people have access to the care to which they are entitled.** However, this assessment framework should be co-created by people who draw on social care, social care provider organisations and networks, and local authorities to ensure it captures what matters to people affected by dementia and is proportionate.

5. Improvement and personalisation

The new duty within the Bill to improve quality of care is welcome but could be strengthened further. It would benefit from including **broadening access to support; clarifying that quality having choice and control over care, the ability to set your own goals, and support to stay part of your community by recognising the value of relationships are all core elements of care quality;** and improving people's experience of living well. Research shows for people with dementia, living well includes measures of psychological factors including optimism, self-esteem, loneliness and depression.

The new Duty within the Bill in respect of research should **include promoting opportunities for people drawing on services to engage in research.** We know that lived experience engagement with dementia research, both biomedical and care research, is low, meaning there are few evidence-based care interventions. This could help to drive this.