

Written evidence submitted by the Alzheimer's Society (HCB75)

1. Alzheimer's Society

1.1 Alzheimer's Society is the UK's leading dementia charity: campaigning for change, funding research to find a cure, and providing quality services to people with dementia and those who care for them. It works in England, Wales, and Northern Ireland, and provides information and support to people with all forms of dementia and their carers through its publications, dementia helplines, and local services. It also funds research, advises professionals, and campaigns for improved health and social care as well as greater public awareness and understanding of dementia.

2. Summary of Key Points

2.1 While the Health and Care Bill's focus on the integration of health and social care is welcome, the Bill itself centres around, and is driven by, NHS provision, resources, and priorities. Social care providers and local authorities must be treated as equal partners from the outset in order to achieve meaningful integration.

2.2 It is difficult to anticipate how successful the Bill's proposals on integration will be in the absence of a clear plan for social care reform. Recent announcements on how social care will be funded are not a solution in and of themselves: ahead of ICSs coming into effect, the Government must produce a vision for social care that details more specific plans.

2.3 There needs to be greater recognition of the importance of the Voluntary, Community, and Social Enterprise (VCSE) sector within the Bill – the sector is a key policymaking and strategic delivery partner, and a primary route to ensuring the perspectives of people with lived experience make a full, active, and much-needed contribution within new structures and planning.

2.4 The Bill lacks vision on how system integration would bring about more personalised care at an individual level. This personalisation would help ensure that people living with dementia receive care that is tailored to their wants and needs, that offers choice and control, and that enables them to live with meaning, purpose, and connection.

3. Introduction

3.1 People with dementia are one of the largest groups that could benefit from improved integration between health and social care.

3.2 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

3.3 Dementia is a progressive, long-term health condition with huge care costs attached. It has been estimated that 70% of care home residents and over 60% of home care recipients are people with dementia.²

3.4 At present, there is no meaningful treatment or cure for dementia available on the NHS. People with dementia are also considerably more likely to have multiple health conditions, with over 90%

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>.

having one or more additional comorbidities.³

3.5 While dementia is a physical health condition, due to the absence of any significant pharmacological interventions, the majority of people with dementia will draw their support from social care, rather than the NHS, once they have received a diagnosis.

3.6 Given people with dementia are one of the biggest groups of patients who cut across both health and social care, improvements in dementia care should be a key performance indicator of the success of the integrated changes. The complexity of dementia means success in this area would be the core measure of an improving, effective and efficient integrated system.

3.7 Integration is not only fundamental to high-quality dementia care – it also has the capacity to particularly benefit people affected by dementia and their carers. Although too many people with dementia currently receive uncoordinated, noncomplementary, or insufficient health and social care, the Health and Care Bill offers a huge opportunity to utilise greater integration for the delivery of high-quality personalised care that is tailored to the wants and needs of the individual.

4. Integration and Social Care Reform

4.1 While the Bill does largely drive and centre on NHS provision, resources, and priorities, it also presents an opportunity to ensure that social care providers and local authorities are treated as equal partners to the health service from the outset. This will help ensure that integration is best placed to deliver personalised care that offers choice and control, responds to changing needs, actively seeks feedback, and encourages and supports people to maintain their independence. As mentioned in point 3.6, improvements in dementia care will be a key performance indicator of the success of integration overall.

4.2 To ensure that this opportunity to enable greater parity between different parts of the system is utilised, it's vital that the language of the Bill overtly promotes a sense of partnership, and that social care is well-represented in the structures established through the Bill. More broadly, the Triple Aim should have regard for resources of the care system and people who draw on it.

Alzheimer's Society recommends that the Committee:

- ✓ Amends the language of Clause 13 on the duty to establish Integrated Care Boards (ICBs) to ensure that its statement that 'NHS England (NHSE) must establish bodies called integrated care boards' is not misinterpreted as meaning that NHSE is the 'lead' in ICBs. ICBs are intended to be (and should be) partnerships, and this must be emphasised further.
- ✓ Ensures that in Clauses 12 and 20 there is representation on ICBs and Integrated Care Partnerships (ICPs) for social care, including commissioners, providers, and voluntary groups. We welcome amendments already tabled by Anne Marie Morris MP on introducing an annual parity of esteem report and reporting on meeting parity of outcomes with social care.

4.3 While we welcome the new duties for regular workforce strategic planning for the health workforce in **Clause 33** of the Bill, it's vital that the Government recognises the importance of support for social care staff too.

³ Browne, J. et al. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. 2017. BMJ Open 7 (3). <https://research-information.bris.ac.uk/ws/portalfiles/portal/120965391/e012546.full.pdf>.

Alzheimer's Society recommends that the Committee:

- ✓ Amends the language of Clause 33 (report on assessing and meeting workforce needs) so that (1) reads 'The Secretary of State must, at least once every five years, publish a report describing the system in place for assessing and meeting the workforce needs of the health service **and social care** in England.' We welcome amendments already tabled by Anne Marie Morris MP on changing five-yearly workforce assessments to annual assessments, and on enforcing the annual publication of a report on integrating and standardising training programmes across health and care.
- ✓ Requests the Government works with staff and other stakeholders to develop and publish a People Plan for social care to pair with the NHS people plan. In such a plan's proposals for improving staff skills, recruitment, and retention, the needs and aspirations of those who use social care must be reflected.

4.4 We all want to live in the place we call home, with the people and things that we love, in communities where we look out for one another, doing the things that matter to us. The next decade presents new opportunities to transform social care and deliver on the vision for what a better social care system should be for those who matter most – those who draw on care and support.⁴

4.5 The reforms to the health system set out in the Health and Care Bill, including for more integration of health and social care, will not work without a proper plan for social care.⁵ Building back better will require a different narrative and approach from what has come before.

4.6 While in recent days, the Government has indicated a plan detailing an overhaul of how the social care system will be funded, this is a vehicle for further reform, rather than meaningful reform in and of itself. Our newly-launched report, [Stabilise, Energise, Realise: a long term plan for social care](https://www.alzheimers.org.uk/sites/default/files/2021-08/stabilise-energise-realise-report.pdf), lays out a comprehensive ten-year plan for social care that is shaped by 30 recommendations across seven key areas.

Alzheimer's Society calls on the Committee to:

- ✓ Urge the Government to bring forward a detailed plan for social care reform as soon as possible, and at a minimum before ICSs come into effect. This must address key challenges not only on funding, but also on workforce and on fair, equitable access to high-quality personalised care for people with dementia, in line with our #CuretheCareSystem campaign.

5. Accountability and Involvement

5.1 The Bill takes positive steps forward on enhancing the role of co-production. However, at present, the Bill does not speak to the vital issue of strengthening accountability to local people who draw on care and support. This represents a missed opportunity to support greater transparency in decision-making and enable 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.

5.2 Thus far, the Bill has also missed the opportunity to include and involve VCSEs, which should be considered as equal partners in decision-making rather than an afterthought. Clear structures need

⁴ Alzheimer's Society and Future Health. Stabilise, Energise, Realise: a long term plan for social care. 2021. <https://www.alzheimers.org.uk/sites/default/files/2021-08/stabilise-energise-realise-report.pdf>.

⁵ Ibid.

to be put in place to enable this VCSE involvement in decision-making. ICBs will include nominated representatives of NHS Trusts, primary care providers, and local authorities – a similar structure could provide nomination for representatives of the VCSE.

Alzheimer's Society recommends that the Committee:

- ✓ Works to strengthen local accountability of Integrated Care Systems, Boards, and Partnerships to people who draw on care and organisations which work with them.
- ✓ Secures standard involvement of people representing communities and service users and VCSE organisations on Integrated Care Boards and Partnerships. At present, the legislation sets this up as an ad hoc arrangement at best. This could be done in legislation Clauses 12 and 20 or in the constitution regarded in Schedule 2, Section 13.
- ✓ Proposes that Health and Wellbeing Boards have an ongoing role in scrutinising ongoing implementation of ICS plans, rather than simply as in Clause 14Z52 having a regard to plans at the outset.
- ✓ Enhances and clarifies the role of committees in the context of place-based commissioning as discussed in section 38 of the Bill's explanatory memorandum.

5.3 Alzheimer's Society is also a member of the Richmond Group of Charities, and supports its amendments to the Bill, including on improving accountability to local people and involvement of the VCSE sector.

5.4 We welcome Clause 121 (Regulation of local authority functions relating to adult social care)'s introduction of a new responsibility for the Care Quality Commission (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, Alzheimer's Society recommends that the Committee:

- ✓ Amends Clause 121 to ensure that the assessment framework that's outlined is 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.

6. Improvement, Personalisation, and Evidence-Based Care

6.1 Clause 19 of the Bill (General functions) contains a welcome duty to improvement in quality of services through ICBs, but Alzheimer's Society believes that this could be strengthened further. Safety and support with basic needs are crucial, but this is too narrow a view of quality.

6.2 Support services, particularly from social care, are often too transactional and driven by time and task. Instead, these services should be driven by connection, purpose, and genuine outcomes. Due to a lack of funding and an overstretched workforce, provision often focuses on basic personal care. This, however, does not necessarily offer people a good quality of life. Research shows that for people with dementia, living well includes measures of psychological factors such as optimism, self-esteem, loneliness, and depression.⁶

6.3 An essential component of integrating care and support for people with dementia is to work in

⁶ Clare, Linda et al. A Comprehensive Model of Factors Associated With Subjective Perceptions of "Living Well" With Dementia. 2019. Alzheimer Disease & Associated Disorders 33 (1).
https://journals.lww.com/alzheimerjournal/fulltext/2019/01000/a_comprehensive_model_of_factors_associated_with.6.aspx.

partnership with the person receiving that care and support, and those who care for them, to understand what matters to them in their care.

Alzheimer's Society recommends that the Committee:

- ✓ Broadens Clause 19's Duty as to improvement in quality of services to include a duty to increase access to support to more people and to ensure that people drawing on care are able to access care that meets their level of need.
- ✓ Ensures that guidance associated with this legislation clearly sets out what quality means in the context of the Bill. This definition should recognise the importance of personalisation, and clarify that quality means offering individuals: choice and control over their care; the ability to set their own goals (which could be a guide for holistic needs as well as medical needs); support to stay part of their community; and support to live well with a long-term condition.

6.4 There is also scope to broaden Clause 19's duty in respect of research. As the Bill stands, ICBs would be required to promote research on matters relevant to the health research, and to promote the use of evidence obtained from research within the health service. However, engagement with dementia research (both biomedical and care research) is low, which means that in reality, there are few evidence-based care interventions in the field.⁷ For example, researchers from the Wellbeing and Health for People with Dementia (WHELD) reviewed 170 training manuals for person-centred dementia care and found that in a research setting just four could be proven to be effective.⁸

Alzheimer's Society recommends that the Committee:

- ✓ Amends Clause 19's duty in respect of research to include a requirement for ICBs to promote opportunities for people drawing on services to engage in research. This could help drive engagement in vital research that could be used to inform evidence-based approaches.

For more information on any of the points raised in this submission or any other aspects of Alzheimer's Society's work, please contact Alex Osborne (Public Affairs Officer) at alex.osborne@alzheimers.org.uk.

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⁷ Figures from the NHS' latest Join Dementia Research dataset indicates that just 2% of people diagnosed with dementia in England are registered with Join Dementia Research: **NHS Join Dementia Research**, Join Dementia Research Volunteer Registration Data, September 2019. <https://nhs.joindementiaresearch.nihr.ac.uk/wp-content/uploads/JDR-Extract-Report-20210901.xlsx>.

⁸ **Ballard, C. et al.** Improving mental health and reducing antipsychotic use in people with dementia in care homes: the WHELD research programme including two RCTs. Programme Grants for Applied Research, Volume 8, Issue 6, July 2020.