

## Alzheimer's Society

# Alzheimer's Society response to the Health and Social Care Committee's call for evidence on the Social Services and Wellbeing (Wales) Bill

March 2013

Consultation Response

Tuesday, 19 March 2013

To Whom It May Concern:

Alzheimer's Society welcomes the introduction of the draft Social Services and Wellbeing (Wales) Bill. In particular, we welcome the emphasis on preventative services, the development of a National Eligibility Framework, the portability of care plans, and the entitlement of carers to their own needs assessments. The aims and objectives of the Bill are ambitious and have the potential to improve quality of life for people with dementia in Wales. However, there are some areas where we believe that the current draft of the Bill lacks either the clarity or the strength to deliver its stated purpose. This includes provision of information, advice and guidance, preventative services and integration of health and social care services.

### **1. Alzheimer's Society**

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications National Dementia Helpline, website and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

### **2. Dementia in Wales**

There are currently estimated to be over 17,000 people with dementia in Wales, of whom only 38.5% have received a diagnosis. Over the next 20 years it is predicted that there will be a 31% increase in the numbers of people with dementia and in some parts of Wales such as Powys and Ceredigion that increase will be as much as 44%.

Dementia is a complex condition and people with dementia have specialist care needs. People with dementia aspire for the support and care they receive to enable them to remain independent, active and socially engaged. Assumptions should not be made that people with dementia cannot enjoy a good quality of life or express needs and preferences.

Providing care to people with dementia is a core business of the social care sector. It is therefore essential that the provisions of the Social Services and Wellbeing Bill work well for people with dementia.

Alzheimer's Society looks forward to continuing to work closely with Welsh Government to improve the lives of people with dementia in Wales.

### 3. Consultation questions

#### 3.1. Is there a need for a Bill to provide for a single Act for Wales that brings together local authorities' and partners' duties and functions in relation to improving the well-being of people who need care and support and carers who need support?

Alzheimer's Society welcomes the Social Services and Wellbeing Bill and the opportunity that it provides to consolidate the patchwork of legislation that has built up over the previous decades. It is important that the relationship between the new Bill and previous legislation is made explicit. There are some areas of the Bill which would benefit from being strengthened or clarified in order to fulfil the central aim of improving the wellbeing of people who need care and support and of carers who need support. These concerns are outlined in more detail in responses to the subsequent questions.

#### 3.2. Do you think the Bill, as drafted, delivers the stated objectives as set out in Chapter 3 of the Explanatory Memorandum?

Alzheimer's Society supports the aims and objectives of the Bill as set out in the Explanatory Memorandum. Paragraph 24 of the Memorandum emphasises the importance of promoting an individual's voice and control in relation to access, assessment and eligibility for services. However, Alzheimer's Society does not believe that proposals in this area are sufficiently robust to ensure that they are made accessible to people with dementia. In particular, we are worried that the proposals for 'information, advice and assistance' do not include advocacy.

Alzheimer's Society has recently established an all Wales specialist dementia advocacy service called 'Voice and Choice.' However, access to independent advocacy is currently quite limited. We would like to see access to advocacy services for people with dementia increased and information about using advocates made more widely available to individuals using NHS or social care services.

People with dementia have specific needs that arise from having a condition that is not only progressive and degenerative, but which in the latter stages can result in people losing the capacity to understand others, communicate their wishes, and give or withhold consent. Advocacy services for people with dementia help them to make key decisions in their lives and support them to make the choices that are right for them. Trained professionals work with people with dementia to help them to express their wishes to key professionals, organisations and carers, standing by their side every step of the way. The need for advocacy for people with dementia who face complex issues around social exclusion and deteriorating cognitive function may be much broader than access to statutory services and treatment.

The Mental Capacity Act 2005 (England and Wales) supports the recognition that people with impaired capacity have the right of choice, protection and validation of their wishes and needs. However, the Mental Capacity Act remains significantly under-used and misunderstood. We would encourage Welsh Government to take the opportunity presented by the Social Services and Wellbeing Bill to embed best practice in Wales.

In order to make the provisions of the Bill more accessible to people with dementia, the sections covering the provision of information, advice and assistance need to be significantly strengthened and amended to include specific mention of advocacy.

**3.3. The Bill aims to enable local authorities, together with partners, to meet the challenges that face social services and to begin the process of change through a shared responsibility to promote the well-being of people. Do you feel that the Bill will enable the delivery of social services that are sustainable?**

In order to deliver social services that are sustainable, the Bill needs to do more to tackle the barriers that currently exist to greater integration between health and social care services.

Section 146 of the Bill outlines the circumstances under which a local authority must exercise its social services functions with a view to ensuring the integration of care and support provision with health provision and health-related provision. Moves towards greater integration are very welcome, but in order for services to meet the needs of people with dementia, integration needs to be more fully embedded throughout the Bill. There are currently many barriers to greater co-ordination between health and social services and these are not sufficiently addressed in this draft of the Bill.

Dementia is a complex condition combining features of chronic neurological disease, mental illness, physical frailty and communication problems. This complexity and the fact that people with dementia often move between care settings means that people with dementia often receive formal care from a range of health and social care services. Effective coordination is therefore essential if formal care services are to meet the needs of people with dementia.

Only a quarter of respondents to Alzheimer's Society's 'Support. Stay. Save.' report said the services the person with dementia received worked well together, with over a fifth responding that they did not work well together.<sup>1</sup> Poor coordination is a significant barrier to people with dementia getting the support and care they need. It can inhibit people with dementia's access to care and support, limiting their choices in care and resulting in crisis admissions to hospitals and care homes. Lack of coordination of care contributes to people with dementia remaining in hospital for longer than expected. Counting the Cost found people with dementia stay in hospital far longer than other people admitted for the same reason, partly as a result of lack of coordination of care in the community and also within hospitals themselves.<sup>2</sup>

An important step towards a more integrated experience for people with dementia would be creating care plans that were more holistic, covering health and social care services, and based on involvement of the person with

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<sup>1</sup> Alzheimer's Society, Support. Stay. Save, (2011)

<sup>2</sup> Alzheimer's Society, Counting the Cost (2009)

dementia, their carer and family and professionals. Care services should be based around this care plan, rather than organisational or services boundaries. Commissioning should also be a joint and collaborative exercise between health and social care, based on local needs assessment and focused on quality. Co-production is another important element of an integrated experience of care: People with dementia and their carers should be involved in the commissioning process and in informing the design and delivery of services.

### **3.4. How will the Bill change existing social services provision and what impact will such changes have, if any?**

Alzheimer's Society welcomes both the preventative approach and the development of a National Eligibility Framework. A preventative approach may ensure that people get support early on, when we know that it can be most beneficial and cost-effective. A National Eligibility Framework may bring greater clarity to decisions about who qualifies for care and help end the postcode lottery in access to services. However, there are important ways in which we believe that both of these proposals could be strengthened. Criteria for eligibility need to be set at a level that supports the emphasis on prevention and early intervention. Services, including preventative ones, need to take due account of individual service-users aspirations.

We are concerned that we have not received any indication of how the eligibility criteria will be determined. As described in the Care and Social Services Inspectorate Wales and Healthcare Inspectorate Wales review report, there is an inherent tension between the preventative approach emphasised in the Bill and an eligibility framework which prioritises the highest need.<sup>3</sup> The Bill will only be able to promote early intervention and preventative services if the bar for eligibility is set at a fair and reasonable level. The National Eligibility Framework must have the effect of improving consistency of support across Wales rather than further rationing the support which people are able to receive. We support the position taken by the Wales Carers Alliance that if eligibility criteria are set too high then this will have a negative impact on the aspirations for prevention and wellbeing that are contained within the Bill. It is also essential that there is sufficient monitoring of adherence to the Framework.

In addition to suggesting that aspects of the Bill need to be strengthened in order overcome this potential tension and to meet the Bill's aspirations around preventative services, Alzheimer's Society would also suggest that the definition of prevention could be broadened to also take account of the individual's own aspirations. Such an approach would be in line with Welsh Government's recent consultation on introducing a national outcomes framework for social services in Wales and supportive of the emphasis on improving wellbeing.

However, specific attention would be required to ensure that people with dementia were able to fully benefit from this emphasis on individual

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<sup>3</sup> CSSIW and HIW, Growing old my way: a review of the impact of the National Service Framework for Older People in Wales (2012)

aspirations. Too often it is assumed that people with dementia cannot enjoy a good quality of life or express needs and preferences. In order to counteract this, it is essential that all relevant staff have training in how to support people to live well with dementia.

### **3.5. What are the potential barriers to implementing the provisions of the Bill (if any) and does the Bill take account of them?**

Alzheimer's Society believes that the main barrier to implementing the provisions of the Bill will be financial. At present, social care is significantly underfunded. We are concerned that in the absence of a sustainable funding settlement, costs may increasingly be transferred to service users. The Bill contains provisions for charging for several services, including preventative services and the provision of information, advice and assistance. Welsh Government needs to do more to demonstrate that the Bill will not create additional costs that will be transferred to service users.

Charging for care affects people with dementia and carers more than older people with other medical conditions. Despite dementia being a physical disease of the brain, most of the essential care required as a result of the disease comes from social services. Dementia can last for many years and this can mean significant bills for care. The Society has campaigned for many years to end the 'dementia tax' - where every year tens of thousands of families are left to pay all their care costs whilst other diseases are paid for by the NHS. In addition, people with dementia and carers are paying for services that often do not deliver good quality care. Westminster's response to the Dilnot Commission's proposals will need to be enacted in Wales, but more money above and beyond this will be necessary to meet the gap in social care funding.

The Social Services and Wellbeing Bill is a landmark opportunity to improve social services in Wales. However, it is essential that financial concerns are not allowed to undermine the ambitious aims and objectives of the Bill. We would urge Welsh Government to ensure that the Bill has been thoroughly and adequately costed.

Alzheimer's Society looks forward to continuing to work with the Health and Social Care Committee as the Social Care and Wellbeing Bill progresses. We would welcome the opportunity to comment on this legislation further and in particular to give oral evidence to the Committee.

Yours faithfully,

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