

Dr Dai Lloyd AM
Health, Social Care and Sport Committee
National Assembly for Wales
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30 July 2019

Ref: Health, Social Care and Sport Committee inquiry into the Health and Social Care (Quality and Engagement) (Wales) Bill: Alzheimer's Society Cymru response

Dear Dai Lloyd AM

I am pleased to respond on behalf of Alzheimer's Society Cymru to the [Health, Social Care and Sport Committee inquiry into the Health and Social Care \(Quality and Engagement\) \(Wales\) Bill](#). Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia. Alzheimer's Society Cymru welcomes the Committee's interest in the Health and Social Care (Quality and Engagement) (Wales) Bill.

Reform

Alzheimer's Society Cymru currently holds the same belief as the NHS Confederation¹, in that the Community Health Councils are in dire need of reform. The Councils have been in existence since 1974, and with the last reform in Wales taking place in 2010, when numbers were reduced from 19 to eight.

However, whilst we advocate the need for reform, we are conscious that the Welsh Government cannot make the same mistakes as the Westminster Government in undertaking this reform. The new English structure, Public and Patient Involvement Forums, was established in 2003. These were replaced by local involvement networks (LINKs) and these have now also been superseded in NHS England by the establishment - as a result of the English NHS reforms in 2012 - by new organisations called Healthwatch. These do not, however, have the same resources, statutory powers or responsibilities as CHCs. All indications show that this process was drawn out, error ridden, and did not take the voice of the patient seriously. The health system in Wales can ill afford to make these mistakes.

Alzheimer's Society Cymru is pleased to see that the proposals in the Health and Social Care (Quality and Engagement) (Wales) Bill make provision for the inclusion of social care in the duties of quality and candour. This is a long overdue step, and one that will hopefully lead to the improvement of the care undertaken in the sector in Wales for people living with dementia, their carers and families.

As mentioned above, Alzheimer's Society Cymru has some concerns and reservations about the Bill, its provisions and structures, and our detailed response to these are laid out below. Where possible, we have also striven to outline possible solutions to these concerns.

Visibility

Alzheimer's Society Cymru currently has concerns around the existing knowledge and understanding of the role of Community Health Councils in Wales amongst the general populace. We are concerned that people who are in need of support from Community Health Councils are unaware that these mechanisms exist currently, and we would like Welsh Government to avoid this lack of knowledge persisting, with the implementation of this new body.

Therefore, we call on the Welsh Government to ensure that the new body, its role and function within the health and care service is marketed correctly to allow practitioners, patients and the general public to be aware of the role of the body, and to be aware of how to refer to the new body, where appropriate, and what the stated aims and outcomes are for the new body.

We believe that this extra knowledge will dramatically increase the effectiveness of the new body, and allow them to discharge their functions around the duties of candour and quality in an effective way that best serves the population of Wales.

Locality

Whilst Alzheimer's Society Cymru agrees with, and understands the need for a central body to oversee the process under the Health and Social Care (Quality and Engagement) (Wales) Bill, there are issues that arise from this centralisation that must be addressed by Welsh Government.

Alzheimer's Society Cymru maintains that there must be some form of local representation that sits underneath the proposed 'Citizens Voice Board.' This local knowledge is central to understanding the challenges that are faced in different health board areas. We are aware that many of the larger issues will be Wales wide, but the nuances that affect these will vary greatly by city, town and village, let alone health board area, and so we would advocate strongly for some form of local representation to remain underneath the proposed board.

Finally, we are keen to ensure that the Local Health Boards have confidence that their views will be taken into account by the new 'Citizen's Voice Board' and that the board does not become too 'Cardiff centric,' an accusation that has been levelled at Welsh Government initiatives previously. Ensuring that the views of the Local Health Boards, alongside those of their patients are taken into account is key to ensuring the success of the new Board and system, as we absolutely must ensure that we build a health service and social care sector that benefits people the length and breadth of Wales equally. Therefore, we would strongly advocate that the Local Health Boards are active partners in the new system, and that local knowledge and views are represented, and tapped into at all times.

Advocacy & Inspection

Through our discussions with other third sector bodies on the Health and Social Care (Quality and Engagement) (Wales) Bill, Alzheimer's Society Cymru has become aware of a school of thought that has inferred from the Bill that if a person is already receiving advocacy services from an outside agency, such as ourselves, then they have no access to advocacy under the 'Duty of Candour' procedure outlined in Bill. Alzheimer's Society Cymru would therefore advocate that the Welsh Government seeks to guarantee that this Bill dovetails with the Social Services and Wellbeing Act to ensure that access to advocacy is maintained, and works in harmony with the new Citizen's Voice Board proposed in this Bill.

Alzheimer's Society Cymru is also concerned that the current inspection function given to existing Community Health Councils is being removed under the Bill. Whilst this function is not executed

as often as it possibly should be, we believe that this is still an important function that will have a large role to play under the provisions in the Bill, and we would like to see this function maintained to allow local bodies underneath the Citizen's Voice Board to carry out inspections on underperforming functions of health and social care.

Funding and Personnel

Finally, Alzheimer's Society Cymru has concerns regarding the number of representatives on the new Citizen's Voice Board, and the amount of the support the Board will be given to discharge its functions. Whilst we are aware that the current system of Community Health Councils is overbearing and bloated, we believe that eight people sitting on the Citizen's Voice Board is not enough to adequately cover the workload and functions to cover the whole of the health and social care systems in Wales.

We also have concerns about the number of people due to sit on the board. We fully believe that eight members is not going to be sufficient to cover the wide range of conditions that interact with the health and social care services and will be covered under the provisions on the new Bill. We are therefore concerned that issues that relate to one specific condition, such as dementia, which has wide ranging implications across health and social care, will be misrepresented or misunderstood, leading the Board to make decisions that are wholly inadequate for people living with and affected by dementia.

Alzheimer's Society Cymru also believes that a robust appeals process, either to Welsh Ministers or to another body, must be put in place for the Board and its decision making to be effective. Without an appeals process in place, Alzheimer's Society Cymru is worried that the Board will not be held to account over the decisions it makes. We therefore advocate that the Welsh Government seeks to implement an appeals process.

Lastly, Alzheimer's Society Cymru has concerns around the funding allocated to the new Board to undertake its work. Currently, we believe that the funding allocated to the Community Health Councils is around £4,000,000. We have heard that the funding to be allocated to the new Board is going to be £4,700,000. We do not believe that allocating an extra £700,000 is going to provide adequate funding to allow the Board to cover all of the health and social care sectors. We therefore advocate that the Welsh Government seeks to allocate more funding.

Solutions

Despite the issues outlined above, Alzheimer's Society Cymru welcomes the Bill as introduced, and believes that, with minor amends to the Bill, it will provide much needed reform to the Community Health Councils, and improve the quality of care offered in both the health and social care sectors in Wales. With this in mind, we would like to once again outline our solutions to the issues we have raised above.

Firstly, we would like to see strict Welsh Government guidance around the visibility and work of the Citizen's Voice Board, to increase public knowledge, as without this knowledge, the Board will not be able to effectively discharge its duties.

Secondly, we would like to see the Welsh Government consider the formation of local groups to feed into the work of the Citizen's Voice Board. This would ensure that the Board has access to a network of local knowledge, whilst ensuring that Health Boards and Local Authorities who run social care services have a mechanism to feed into, and challenge the national Board where appropriate.

Thirdly, Alzheimer's Society Cymru believes that there should be at least one person living with dementia, and one carer of a person living with dementia, on the Citizens Voice Board, and the local groups. This would ensure that the 45,000 people living with dementia in Wales, and their carers, are represented. As we have previously stated in evidence to the Committee and to the Welsh Government, given the wide-ranging impact of dementia on individuals' health and social care needs, if you get it right for people living with dementia, you get it right for everyone.

Finally, we would like to see the inclusion of advocacy across the various sectors in Wales. We would like the Welsh Government to ensure advocacy services provided by the third sector, and other bodies, have access to the Duty of Candour process to ensure that people are not excluded from the process by being proactive and engaging external advocacy.

Conclusion

We welcome the Health, Social Care and Sport Committee's interest in providing this level of scrutiny to the Health and Social Care (Quality and Engagement) (Wales) Bill. The evidence above was written in order to show the Committee that whilst the Bill has some positive aspects there is still a large amount of work to do if we are to achieve the quality and engagement that the Bill envisages.

We hope that evidence contained in this document is informative and will help the committee accurately examine the Bill and place recommendations on the Welsh Government in order to improve the Health and Social Care (Quality and Engagement) (Wales) Bill.

If you require any further information, please do not hesitate to contact me.

Yours sincerely



Sue Phelps

Country Director, Alzheimer's Society Cymru