



Consultation Response
The Health and Social Care (Quality and Engagement) (Wales) Bill
Health, Social Care and Sport Committee
National Assembly for Wales
July 2019

Introduction

Age Cymru is the leading charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We are pleased to respond to the Health, Social Care and Sport Committee's consultation on the Health and Social Care (Quality and Engagement) (Wales) Bill 2019.

System-wide working and person-centred care

According to the Explanatory Memorandum, one purpose of the Bill is to ensure that improving quality becomes a system-wide way of working, with the focus on outcomes, and the person at the centre. Another is to drive service integration between health and social care. We support these intentions.

However, we are concerned that, while the new duty is placed only on NHS bodies, and while local authorities already have an equivalent duty under the Social Services and Well-Being (Wales) Act 2014, there is no duty on the NHS and LAs to co-operate on quality across the health and social care systems. We believe that this is a missed opportunity for addressing cross-boundary service quality issues in relation to, eg, transfers of care and the lack of clinical skills available in care homes, where knowledge and skills need to flow across organisational boundaries, and where services need to be integrated to ensure the best possible outcome for the person at the centre.

Transfers of care

Through our work with My Home Life Cymru, we are aware of numerous examples where a duty to co-operate across health and care systems would dramatically improve the quality of care for people being transferred from care home to hospital settings and vice versa. We believe it is essential that NHS staff recognise that,

where an older person is living in a care home, the care home is his or her home and that care home staff are just as much his or her day to day carers as family and friends are for people living in other settings. Care home staff who care for their residents day to day have a wealth of information about that individual which could transform the quality of their care in hospital, but existing professional boundaries militate against the engagement of care home staff, and even against informing them at a very basic level of how their resident is while the resident is in hospital.

We would like to see a duty to co-operate across NHS and social care boundaries lead to greater professional respect for the expertise of care home staff in personalised care. Care home staff are skilled at working with individuals with complex needs and want to share their expertise. However, they report that hospital staff never ask, eg, what helps this person drink or sleep, or how they signal they need to go to the toilet. Care home staff are frequently not told what rehabilitation their residents have had in hospital, which could be continued in the care home. Families are routinely given this information, but care home staff are not.

We know of numerous cases where people with dementia have returned to care homes from hospital unrecognisable from when they went in, because they were not treated in hospital the way they were cared for in the home. For example:

- people returning to the home doubly incontinent, because hospital staff did not know how they signalled their need for the toilet;
- people who were walking in the care home come back from hospital in wheelchairs, needing hoists, with sores they did not have before;
- people who will only drink from a particular cup come back to care homes from hospital dehydrated, when care home staff could have brought the cup they needed to the ward for them.

Without the short-term memory to re-learn lost skills, it is next to impossible to restore people's abilities. Their hospital stay has disabled them. This means that either the care home has to charge more money for their care, or the person has to move to a nursing home, which is very distressing for everyone concerned. For this reason, many care home staff are terrified of residents going into hospital, and keep them at home until there is an emergency.

Some people are discharged to a care home with no information, unexpectedly. We heard of a gentleman who was dropped off at the care home, with no prior notice, at 1.00 am in his hospital gown with a bag of pills, when there was no-one available at the care home to take care of him appropriately. The care home sent him back to hospital because this was an unsafe discharge, and he died that night.

We would like to see a duty to co-operate across health and social care boundaries lead to strengthened relationships with health care professionals, especially hospital staff, in the interests of truly person-centred care.

Lack of clinical skills in care homes

We are aware of numerous examples where a duty to co-operate across health and care systems would drive integrated care provision by making clinical skills more widely available in care homes, including:

- blood pressure and temperature readings. These are simple tests which people do themselves at home. However, because of rigid professional boundaries, care home staff may have to wait hours for a GP to attend to take them;
- care home staff are told by clinical staff that they are not qualified to lift someone after a fall, yet NHS emergency services frequently treat someone who has fallen in a care home as a lower priority than someone who has fallen at home. The average wait for a paramedic is 8-10 hours. We know of one case where a gentleman was on the floor for 40 hours, getting cold, being cuddled and covered with blankets, waiting for the ambulance to arrive;
- inserting and changing fluid drips and the use of morphine pumps, at the end of life, should be skills readily available in end of life care in care home settings, so that people can die in their home, where they would prefer to be and where their relatives prefer to visit them, and not in hospital. We also believe that Care Inspectorate Wales' focus on mortality statistics as an indicator of the quality of a care home is not appropriate. People are now entering care homes later in life, and the average life expectancy in a care home is 18 months. We are concerned that many care homes are so afraid of the impact of mortality rates as an indicator of the quality of their care that they are sending residents to hospital to die, instead of allowing them to die in their home.

We therefore propose that the Bill should include a duty on both NHS and bodies and local authorities to co-operate on quality across the health and social care systems.

Duty of candour

We support the provision in the Bill for a duty of candour, and particularly that an NHS body must notify a service user or someone acting on their behalf as soon as they know the duty of candour has been triggered.

We would like to see recognition in the NHS that sometimes, care staff are the most appropriate people to be notified. All too often, care home staff are told that information about their residents' wellbeing can be given only to the person's next of kin – who may be old themselves, overseas, or unable to make phone calls or otherwise act on the resident's behalf. We believe that care home staff should be kept in the loop about the welfare of their residents, not in ignorance, and that they should be notified that the duty of candour has been triggered, when appropriate.

New Citizen Voice body

We welcome the establishment of the new Citizen Voice body. The new body will need to engage with a large number of third sector organisations as well as members of the public. Older people are by far the biggest users of NHS services. As Wales' leading older people's charity, Age Cymru is well placed to support and inform the new body; we also work with extensive networks of older people, including Pensioners' Forum Wales, the Welsh Senate of Older People, Cymru Older People's

Alliance, and Age Alliance Wales, a powerful alliance of 24 national voluntary organisations committed to working together to develop the legislative, policy and resource frameworks that will improve the lives of older people in Wales. Each of these would be able to make a valuable contribution to the work of the new body.

We are, however, concerned that the Citizen Voice body has the function of making representations to NHS bodies and local authorities about the provision of health or social services and any changes in those services – but again, not apparently about integration of them. We would like to see the new body's remit extended to reflect a new statutory duty on NHS bodies and local authorities to co-operate across boundaries in the interests of person centred care.

We support the view of the Board of Community Health Councils in Wales that the new body should have all the tools it needs to be strong, independent and effective in representing the interests of people in health and social care, and that it should be accessible locally, in person, by people who cannot leave the place where they are and who need advocacy support.

Age Cymru's local partners report that, often, people find that they cannot communicate effectively with health and social care professionals. One of our local partners has recently encountered four cases where people have been discharged from hospital without proper planning, and they or their carers have not been allocated an advocate, on the assumption that the person did not need an advocate because they had family. In other cases, NHS staff were not consulting with the patient's family despite the fact that they had pleaded with the staff to discuss their relative's treatment with them as she had dementia and would not remember what the clinicians told her.

Examples like this make effective recourse to a citizen's voice body essential. We believe that an important role of the new body should be to bring about culture change by modelling best practice in complex situations like these, and setting an example to health and social services of excellence in eliciting and acting upon the service user voice. The 2019 edition of Age Cymru's discussion journal, *EnvisAGE*, took as its theme voice, choice and control in later life. An electronic copy is available at <https://www.ageuk.org.uk/cymru/our-impact/policy-publications/envisage/> We should be delighted to make copies available to the new body when it is appointed.