Response to:

The National Assembly for Wales' Health and Social Care Committee inquiry into **residential care for older people.**

On behalf of the Dementia Services Development Centre for Wales, Bangor University (DSDC Wales)

1. **DSDC Wales** was established in 1999, and was a founding member of a network of such centres across the UK and Ireland. All had a remit to provide information regarding dementia care and services, training for staff working in dementia care, care-related research, and consultancy and advice for dementia service development. It was established as a partnership between Bangor University and an NHS service development team in Cardiff. It's funding has primarily come from charitable and university sources and income from training, together with some grant funding from the Welsh Government.

- DSDC Wales produces 'Signpost' a practitioner magazine, for those working with older people with mental health difficulties. This is a resource, providing information, up-dates and innovative ideas for those working in this field. DSDC Wales organises and supports a number of relevant seminars and conferences, including a series of joint conferences in Bangor with the charity 'RESEC' (Research in Specialist Elderly Care), and major events on younger people with dementia, jointly with the Alzheimer's Society.

- DSDC Wales has had a significant training function for many years, which has been greatly augmented in the current financial year by a significant grant from the Welsh Government, funding the Dementia Care Training Initiative for Wales. DSDC Wales offers a 6-module certificate programme, accredited by Agored Cymru, on working with people with dementia and their families. This is available at Levels 1, 2 and 3. Many of those who have completed this programme, or are currently undertaking it, are care home staff. As part of the Dementia Care Training Initiative, a further 'train the trainers' module has been accredited, which aims to add to the capacity for dementia care training in Wales. Training is commissioned by a number of local authorities (who make a proportion of places available to the independent sector), health boards and directly by independent sector care home providers or community care providers.

- DSDC Wales has advised on a number of service developments, including care home design. This has enabled care homes to incorporate leading edge aspects of design for dementia in new build and extension projects.

- In November 2011, DSDC Wales delivered to CSSIW a report, commissioned by CSSIW, on a consultation regarding the proposed discontinuation of the 'dementia' category in relation to care homes in Wales.

- DSDC Wales has a significant research portfolio. It hosts NEURODEM Cymru, the Wales Dementias and Neurodegenerative Diseases Research Network, funded by NISCHR. Research studies focussing on care homes in Wales have been funded by the Wellcome Trust and the

Medical Research Council, and the Department of Health (with Comic Relief) funded a project to explore factors underpinning dignity in care homes (PEACH – Promoting Excellence in All Care Homes), where field work was undertaken in care homes in England. DSDC Wales provides expertise to three major NIHR funded programme grants, based at universities in England, developing interventions to improve quality of life of people with dementia in care homes, reducing challenging behaviour and reducing use of anti-psychotic medication. NEURODEM Cymru is seeking to establish a Research Development Group, bringing together researchers, care home staff and providers, service users and carers to further develop research in care home settings.

DSDC Wales is therefore well-placed to advise on the situation in care homes in Wales, specifically in relation to people with dementia.

2. **Support for people with dementia** is in effect the core business of care homes. There are approximately 40,000 people living with dementia in Wales, according to the authoritative Dementia UK report (2007). This number is expected to increase by nearly a third by the year 2021. Estimates suggest that 37% of people with dementia live in care homes, with the proportion rising from 27% of people with dementia aged 65-74 to 61% of those over 90. The increase in numbers of people with dementia over the next 10-20 years is greatest in the oldest old, the group currently most at risk of care home placement, perhaps resulting from unavailability of family support.

Dementia is the strongest determinant of entry into residential care in older people, and studies suggest that around **two thirds** of residents living in a care home have some form of dementia. However, only one third of care home places in Wales are registered within the dementia category, and so it is self-evident that there are likely to be as many people with dementia in care home places in Wales outside the dementia category as there are within it. In our report for CSSIW on the use of the dementia category, we note that basing care provision on a diagnostic categorisation rather than on care needs leads to perverse incentives not to make a diagnosis, potentially denying access to therapeutic interventions as they become available. There are numerous examples of people receiving a diagnosis being required to move from one home to another, without any change in their needs having occurred. However, removing the dementia category will require effective systems for ensuring that homes which can support people with dementia who are active and/or whose behaviour is challenging are identifiable, and receive additional funding currently offered by a number of authorities on the basis of the dementia categorisation.

3. In relation to the **process of entering care homes**, and possible alternatives, it is clear that many admissions follow an admission to a general hospital, often for an acute illness superimposed on chronic conditions such as dementia. The care of older people (especially those with dementia) in general hospitals has attracted a great deal of criticism over the years (e.g. the Older People's Commissioner report, 2011; Royal College of Psychiatrists audit, 2010; Alzheimer's Society report 2009 etc.). Making life-changing decisions in a crisis situation is far from ideal, and there is reported to be much scope both for prevention of admission and for rehabilitation and return home, if the dementia is identified and the person's needs recognised.

Assessment of the person's function in an unfamiliar environment is misleading in terms of the person's potential to continue to live in the community. Alternatives to care home placement need to focus on reducing the risk of being placed permanently in a care home following an acute crisis.

This might involve enhanced support for people with dementia returning home, or care homes specialising in recovery and rehabilitation and getting people back to their homes – at the moment there is no incentive to do this, of course. Care homes seldom have physiotherapists and occupational therapists to call on who might assist in the rehabilitation process. For domiciliary care to be a viable alternative for people with dementia, it must be provided in a dementia-friendly fashion: using as few care workers as possible, so that they are able to build a good relationship with the person with dementia, based on knowledge and understanding of the person as a person; a shift away from a task focus to a support focus, providing stimulation and activity, rather than doing things for the person; long enough time slots to enable this different focus; and flexibility to adapt to changes in the person with dementia from day to day.

4. The **capacity of the care home sector** is difficult to gauge. It is not uncommon to hear knowledgeable professionals suggest that there will be little need for care homes in the future, as community care and assistive technology develop further. However, in our view this is mistaken; community care is largely underpinned by the input of family care-givers, and this is likely to be less available in the future for a number of reasons, notably the increases in life expectancy, smaller family size etc. Providing community care for people with dementia is challenging, especially for those who live alone, not least because their perception of their needs for care and support may be drastically different from those of service providers. We envisage a future where care homes will support an even greater proportion of people with dementia – and this has been borne out by our observation of much greater interest (in North Wales at least) in developing new dementia units and converting existing homes to cater more effectively for people with dementia. The withdrawal over a number of years of the NHS from providing continuing care for people with dementia feeds into this trend.

It is unfortunate that the Inquiry focuses only on residential homes. Our view is that in relation to dementia care it can be difficult to distinguish residential and nursing provision, with rather similar residents in each sector, and many homes having a mix of provision. Although some high quality care is being provided by qualified nurses, it is clear that a nursing qualification per se is no guarantee of knowledge or skills in this domain.

We envisage a need for more homes specialising in dementia care – that is the care of people with dementia who are active, and/or whose behaviour is challenging. The diagnosis of dementia per se does not mean that the person requires specialist care. All homes should be able to provide support for people with dementia, because it is commonplace in these settings. This will include support for memory, activities, prompts for self-care etc. All care home environments should be designed with dementia in mind – clear sign-posting, domestic scale, many points of interest, including easy access to outside spaces. Specialist homes will have staff with additional training in assessing the reasons underlying challenging behaviour and developing action plans to address these. There is also likely to be increased need for homes able to provide palliative care for those with advanced dementia and physical co-morbidities.

Training is essential, but it is not the solution to all the difficulties faced. All staff in care homes should have training specifically in relation to dementia care (the NICE-SCIE Guidelines on dementia care, 2006, recommend this and outline areas to be considered). However, training does not lead to enhanced quality of care if it is not backed up and supported by strong leadership, and

encouragement to put into practice insights gained, and to work together as a team to bring about service improvements.

Staff attitudes which incorporate a sense of hopefulness that something valuable can be achieved in working day by day with people with dementia have been shown to be related to higher quality of life in care home residents. Training needs to influence attitudes, as well as skills and knowledge. Some Social Services Training Departments (e.g. Gwynedd and Anglesey) have made a concerted effort to ensure their care home workforce has the opportunity to develop in this area, and have made this training available to independent sector providers in their areas.

5. **Quality of care home services:**

The quality of care homes varies markedly in our experience. We have encountered more good examples in recent years e.g. a local authority home which has developed the involvement of residents in creative arts, bringing in artists to work with residents, culminating in an exhibition at a local gallery; an independent sector home where staff engage residents in day to day activities, and where family members feel welcome and involved.

A number of homes are becoming aware of the adverse effects of anti-psychotic medication, and are engaging in medication reviews and the development of alternative strategies, as envisaged in the 1000 lives plus programme, where a reduction in the use of these drugs, which increase the risk of stroke and death, is a target for both the dementia and the medicines management programmes. In England the goal is to reduce their use by two-thirds. The role of general practitioners in care homes, and their need for a good grounding in care home medicine, is worthy of examination.

The extent of more specialist NHS input to care homes varies markedly. In some areas, there are 'in-reach teams' to provide support from mental health services for older people, in relation to dementia-related difficulties. In some parts of England, the NHS has developed 'challenging behaviour' teams, which can provide intensive, skilled support to care homes in managing these difficulties, often avoiding admissions to hospital. This is a model that could be of real use in Wales.

6. **Regulation and inspection**

Here there is scope for more focus on the quality of care provided, rather than on more structural aspects. The use of an observational tool would be particularly helpful in the dementia care context. In recent years, we have noted that inspectors have more frequently queried training levels and design issues in relation to dementia provision, and this is to be welcomed.

7. **New and emerging models**

Extra care housing is often seen as a potential alternative for care homes. However, in relation to dementia, studies indicate that there is a risk of loneliness, social isolation and even discrimination. It is not thought appropriate for people with advanced dementia to enter extra care. There is the risk for those with milder impairments that if/when their function deteriorates, they will have to move on to a more supportive environment, rather than to age in place. The key to including people with dementia in extra care housing is said to be a flexible approach, which manages any difficulties the person may have that would lead to negative relationships with other tenants (e.g. verbal aggression, incontinence).

Internationally, there is evidence to support the development of small group living environments for people with dementia, with good access to safe outside space, and involvement in both every day and creative activities.

The care home sector has been relatively slow to embrace technologies which could support the provision of care, and free staff time for more person to person contact with residents. This will undoubtedly change in the years to come.

Good quality homes involve fully family members, help them to feel welcome, see them as a resource rather than as a problem. Homes that are more family-friendly have been shown to offer a higher quality of life for residents, and this will be a continued trend. Closer links with the local community, with the home acting as a resource centre, may also bring benefits for residents.

8. **Public / independent balance**

In our experience, lapses in care quality can arise equally in public and independent sector provision. It is evident that the independent sector is often not seen as a partner in the planning of care services or in care provision, and that public sector services continue to have a suspicion of these services, on which the viability of the current profile of care depends. For example, the needs of independent care homes for qualified staff does not seem to appear in the development of training plans for nurses and other professionals in Wales.

9. **Research and Training**

The current Dementia Care Training Initiative finishes at the end of March 2012. It will be important to ensure that the momentum from this initiative is not lost, and that opportunities are offered to those who have undergone the 'train the trainers' initiative to continue their development and receive support as they offer training to others.

NEURODEM plans to establish a Research Development Group, with care home providers, researchers, practitioners, users and carers, to examine ways in which the evidence base regarding care homes can be developed further. We have found that, in general, those care homes who have participated in research projects have benefitted from the involvement, and been generous in their input of time and enthusiasm. Effective ways to disseminate the results of research in this sector need to be identified and developed further.

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