



ADSS Cymru

Leading Social Services in Wales

Yn arwain Gwasanaethau

Cymdeithasol yng Nghymru



WLGA • CLILC

Draft Dementia Strategic Action Plan - Written Evidence for the Health, Social Care & Sport Committee

1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and three fire and rescue authorities are associate members.
2. It seeks to provide representation to local authorities within an emerging policy framework that satisfies the key priorities of our members and delivers a broad range of services that add value to Welsh Local Government and the communities they serve.
3. The Association of Directors of Social Services Cymru (ADSS Cymru) is the professional and strategic leadership organisation for social services in Wales and is composed of statutory Directors of Social Services, and the Heads of Service who support them in delivering social services responsibilities and accountabilities; a group of 80 or so social services leaders across the 22 local authorities in Wales.
4. The rising numbers of people with dementia in Wales is a trend which is common across the world. As the population ages, it has become one of the most important health and social care issues facing us. The number of people living with dementia worldwide today is estimated at 44 million people and is set to almost double by 2030. This predicted rise in numbers and the subsequent increase in costs that will go alongside this will have a significant impact on our health and social care services. We therefore welcome the intention to develop a national strategic action plan, building on previous work such as the National Dementia Vision for Wales. This provides a valuable opportunity for us to be able to identify what we can collectively do in Wales to tackle the challenge of dementia and how we will take this forward together.
5. There are some challenges that are specific to Wales, including the need to address the impact on rural communities, as well as the Welsh Language which is especially important for those who may only understand or be able to communicate in their first language as their illness progresses. We need to plan services to take into account the needs of people who live in rural and urban

settings, and ensure that language and cultural needs and preferences are catered for.

6. We know that the vast majority of people who experience dementia wish to live near their family and carers. They wish to remain within their communities for as long as possible and in the homes of their choice. It is within this context that we must tackle the challenges that dementia brings. We also know that if people receive an early diagnosis of dementia and are given access to appropriate information, support and care, it is possible to live well with dementia. Our ambition must be to ensure that people at whatever stage of the condition are given the best chance to live well and to be as active a part of family and community life as they can. This means ensuring that people who need treatment receive it at the right time and in the right place.
7. As well as improving and developing health and social care services to deal with the dementia challenge, support will also need to be provided by communities, by the third sector, and public and independent sector organisations. Crucially, all services will need to work together in an integrated way, adding value to each and enabling services to be tailored to the individual needs of people affected by dementia, including those diagnosed with early onset dementia. To do this requires a change in attitudes and behaviours towards dementia at all levels of society, which reflect the challenge of demographic change and the impact of dementia. It requires a society in which people with dementia, and those who care for them, are treated with the dignity and respect they deserve, along with the help and support they need.
8. The challenge now, is to develop a determined approach to dementia. An inspired national strategy on dementia is required. There is need for a political and professional commitment at all levels to providing a range of solutions to deliver improved quality of life for people with dementia and their families. Providing true quality of life for people with dementia, means moving away from thinking and focusing on dementia as a disease. The language describing dementia must change. The concept of the Person-Directed/Centered Care Approach for people with dementia first developed by Tom Kitwood is in line with the principles and values promoted in the Social Services Wellbeing (Wales) Act.
9. This approach has since been embraced worldwide as a preferred way of working with people who have dementia, in contrast to the strict medical model of care. A focus on the whole person seeing dementia as a disability of a part of the brain.

We need to focus on the whole person and work to recognise and promote abilities and positively reinforce continued strengths rather than deficits.

10. There are many benefits of shifting care plans for people with dementia from a strictly medical model to a person-directed care focus. The medical model tends to constrain care planning to measuring and focusing on declines, negative issues and occurrences and physical care, rather than on quality of life issues for the person.
11. A person-directed approach looks at the whole person with dementia, what his/her feelings may be in specific situations and why, defines the person's strengths, and attempts to develop an understanding of how to work effectively with that person in ways that empower, reassure and avoid negative stereotypes. This is empowering to those caring and people with dementia because it can offer positive and well-defined strategies that enhance quality of life.
12. For people with dementia, losing the ability to reason can mean navigating their way through the environment and relationships by sensing others around them and reacting to that environment. Much in the way that young children pick up on people's fears, moods, etc. and mirror them back – reacting fearfully when someone is anxious or fearful around them.
13. It is vital to give carers the information that will instill confidence, warmth and a desire to work with the person and get to know them, starting with the care plan. Staff can be free to use creativity and apply knowledge about the person to develop much more effective outcomes which also make their jobs more enjoyable. It is also vital to recognise the contribution of very low paid workforce to community wellbeing and the quality of life for the most vulnerable.
14. Wales needs a long-term vision to ensure we can best meet the challenge of an increasing number of people living with dementia within our population. We fully support the ambition behind the draft strategic action plan to create a dementia friendly nation and we welcome the fact that the action plan is aligned with the ambitions of two of the key pieces of legislation that have been passed in Wales, namely the Well-being of Future Generations Act and the Social Services and Well-being Act. These provide the cornerstone foundations for taking much of this work forward, helping to develop more closely integrated services, more comprehensive programmes of care and a greater awareness and understanding of the needs of

people with dementia and those close to them, such as their families, friends and carers.

15. Whilst we welcome the development of the draft strategic action plan and much of the direction that it sets out we believe further work is needed in order to ensure that this action plan is able to deliver on its ambitions. The draft plan contains a number of proposed key actions required to be able to take forward the key themes identified. However, the action plan does not mention the development of a delivery plan, or something similar, to take these key actions forward, just that a monitoring group will oversee delivery. The vast majority of key actions are broad, with no clear indication of who is responsible, when it needs to be done by, what support or resources are required, nor how we will know that it has been delivered. For example, one of the key actions states that, "health boards and local authorities are to develop specific actions to increase access for individuals who have protected characteristics". It does not however identify what these specific actions should be, what work has already been undertaken, what are the gaps and what actually needs to be done in order to increase access.
16. It is not clear from the plan what scoping work has already been undertaken to identify the evidence behind the actions and therefore where the gaps in services and resources are. For example, one of the key actions is to, "ensure access to services which are non-specialist but can support people with dementia access other assistance needed, e.g. financial advice." We would agree with this, but more work is required to look at scoping what services are already being provided, what the gaps are, who is able to provide these services and what resources are required to support this. It is also not clear from the action plan who is going to lead this work. If we are to deliver the ambitions of the plan then we need a clearer picture of what we need to do, who is going to do it, who else is needed to support this work, by when and how it will be resourced.
17. The strategic action plan does identify some "high level performance measures" to help identify how we will know whether the plan is being delivered. However, it is not clear how these relate back to many of the actions and how they will evidence the outcomes. Only one of the actions identifies a specific target, which is around increases in the number of people formally diagnosed with dementia, which sets the target of an annual 3% increase in identification rates, though it is not clear why this level of increase has been set. Other measures just suggest either an

increase or a decrease would signify whether we know the plan is achieving what it sets out to or not.

18. The plan is very quiet on what resources will be required to support any of this work and what, if any, additional resources are actually available to support its implementation and the significant on-going work that will be required. Spending on improving dementia care is an investment, and one which if invested carefully can transform the lives of individuals, communities and society.
19. It is also not clear who exactly the strategic action plan is aimed at. At times the plan covers what people should expect from services and similarly the expectations that are placed on services. For example, that risk should be considered as part of the care planning and management of people with dementia. Whilst helpful, this would fit better within a guidance document setting out clear expectations for both those affected by dementia and those providing services. The focus of the strategic action plan needs to be on identifying the actions that need to be achieved to provide the type of and level of service required to meet the needs and support people affected by dementia.
20. Throughout the plan there is only one mention of housing. Two thirds of people with dementia live in the community and people with dementia and their carers place great importance on their homes. However, research has found that experiences of housing and housing services are mixed with more needing to be done to link housing with health and social care services. There is a need to recognise that appropriate housing services and support are key mechanisms for effective support of people with dementia in the community. This includes looking at the housing options and tenures available to people with dementia and ensuring that any information and advice includes information on elements such as housing options and sources of funding for adaptations and alterations. There is also a need to consider how people with dementia can have access to homes designed with their needs in mind.
21. Local government have been key partners involved in the Ageing Well in Wales programme from the beginning, which includes a key work strand of developing dementia friendly communities. It is positive to see this work reflected in the plan and it will be important that both the Ageing Well in Wales programme and the work undertaken under this strategic action plan are aligned and complement each other going forward. It is also worth recognising some of the progress that

has already been made by local authorities. For example, across areas such as Gwent and Cardiff significant progress has been made in developing Dementia Friendly Communities and the Social Services Improvement Agency (SSIA) in partnership with local authorities have developed two key resources to support reablement services to work with people with dementia. The first is a guide on the key components the service needs to consider, including a range of good practice examples and standards. The second resource is a training course that authorities can use to support staff in working with people with dementia. The Dewis Cymru website developed by local government has also been launched, designed to help people with their well-being, including those affected by dementia. It provides information to help people think about what matters to them and also provides information and links to people and services in their area that can help support them. The website has a resource directory which includes local, regional and national resources that promote and support well-being, enabling people to see what services and support is available in a particular area that might be of benefit to themselves, their family members / friends or the people they care for, which includes information on dementia.

22. One of the improvement priorities for the newly established Social Care Wales will be around improving services and outcomes for people with dementia. Whilst the detail behind this work is still being developed it will be important that the action plan gives consideration to this work and that they are aligned.
23. The social care workforce, providing direct support to people with dementia needs to be well supported, skilled, and competent. It also needs to be valued and appropriately rewarded. It will become increasingly difficult to recruit and retain these valuable colleagues if these important issues remain unaddressed.
24. The development of a strategic action plan provides us with a golden opportunity to set out our aspirations for what the NHS, local authorities and our partners can deliver over the coming years to meet the significant challenges placed on health and social care services by dementia. The ambitions of the action plan are supported, a dementia-friendly Wales will be a country that creates opportunities for people to age well, in addition to removing the barriers that older people with dementia and their carers face on a daily basis, that interfere with being able to lead meaningful and satisfactory lives. But we need to be clearer about the actions that are required to achieve this, who will lead this work, how we will know whether we are achieving what we set out to do and the resources required and

available to support this work. We need to make sure this strategic action plan creates the opportunity and the foundations to ensure that the vision becomes a reality with the response firmly rooted and grown from its communities and Wales truly becoming a dementia friendly nation.

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