

Agenda – Health, Social Care and Sport Committee

Meeting Venue:

Committee Room 2 – Senedd

Meeting date: Thursday, 2 February
2017

Members' pre-meeting: 09.15

Meeting time: 09.30

For further information contact:

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Informal pre-meeting (09.15 – 09.30)

1 Introductions, apologies, substitutions and declarations of interest

2 Inquiry into medical recruitment – evidence session 1 – Professor Robin Williams

(09.30 – 10.30)

(Pages 1 – 19)

Professor Robin Williams, author of [‘Health Professional Education Investment – Report on the Single Set of Arrangements’](#)

Break (10.30 – 10.45)

3 Inquiry into medical recruitment – evidence session 2 – Trainee panel

(10.45 – 11.45)

Dr Llion Davies

Dr Zahid Khan

Dr Abby Parish

Dr Bethan Roberts



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

Dr Huw Lloyd Williams

4 Motion under Standing Order 17.42 to resolve to exclude the public from item 5 of the meeting

5 Public Health (Wales) Bill – consideration of draft report (1)
(11.45 – 12.30)

(Pages 20 – 82)

Lunch (12.30 – 13.00)

6 Inquiry into the Welsh Government's draft national dementia strategy – evidence session 5 – NHS Confederation

(13.00 – 13.45)

(Pages 83 – 105)

Lin Slater, Assistant Director of Nursing, Aneurin Bevan University Health Board

Dr Suzanne Wood, Consultant in Public Health Medicine, Cardiff and Vale

University Health Board

Nick Johnson, Dementia Care Specialist Facilitator Abertawe Bro Morgannwg

University Health Board

Cecilia Carpenter, Lead Nurse Medical Unit, Abertawe Bro Morgannwg University Health Board

Break (13.45 – 14.00)

7 Inquiry into the Welsh Government's draft national dementia strategy – evidence session 6 – Welsh Local Government Association and the Association of Directors of Social Services

(14.00 – 14.45)

(Pages 106 – 112)

Neil Ayling, Chief Officer, Social Services at Flintshire and President of the Association of Directors of Social Services Cymru

Julie Boothroyd, Head of Adult Services at Monmouthshire, Association of Directors of Social Services Cymru

Naomi Alleyne, Director, Social Services and Housing, Welsh Local Government Association

8 Paper(s) to note

Stage 1 scrutiny of the Public Health (Wales) Bill – Additional information from the Children's Commissioner for Wales

(Page 113)

Stage 1 scrutiny of the Public Health (Wales) Bill – Additional information from the Minister for Social Services and Public Health

(Pages 114 – 115)

Stage 1 scrutiny of the Public Health (Wales) Bill – Additional information from the Royal College of Physicians

(Pages 116 – 117)

Stage 1 scrutiny of the Public Health (Wales) Bill – Additional information from Crohn's and Colitis UK

(Pages 118 – 121)

9 Motion under Standing Order 17.42 to resolve to exclude the public from the remainder of the meeting

10 Inquiry into the Welsh Government's draft national dementia strategy – consideration of evidence

(14.45 – 15.00)

11 Public Health (Wales) Bill – consideration of draft report (2)

(15.00 – 15.30)

Document is Restricted

Agenda Item 5

By virtue of paragraph(s) vi of Standing Order 17.42

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	The Welsh NHS Confederation response to the Health, Social Care and Sport Committee inquiry into the Welsh Government: Together for a Dementia Friendly Wales (2017-22).
Contact	Nesta Lloyd – Jones, Policy and Public Affairs Manager, the Welsh NHS Confederation. [REDACTED] Tel: [REDACTED]
Date:	20 January 2017

Introduction

1. We welcome the opportunity to contribute to the Health, Social Care and Sport Committee inquiry into the Welsh Government: Together for a Dementia Friendly Wales (2017-22). Providing person-centred support and services to people living with dementia and their carers is a priority for the NHS in Wales.
2. The Welsh NHS Confederation represents the seven Health Boards and three NHS Trusts in Wales. The Welsh NHS Confederation supports our members to improve health and well-being by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.
3. While we are pleased to be able to respond to such an important inquiry we would like to highlight our disappointment with the very tight timeframes that the Committee has set. The Welsh NHS Confederation and our members have been given less than a week to provide a written response to the inquiry. While we appreciate that the Welsh Government delayed publishing the draft 'Dementia Strategy' it is very difficult for the NHS to provide a substantive, evidence based, response in such short timeframes, especially on such an important area where there is significant work being done across the NHS to support people affected by dementia. We hope that the Committee considers our concerns when launching future inquiries. Our members will be providing comprehensive responses to the Welsh Government consultation and they will share these with the Committee by the 3rd of April.

Overview

4. Providing person-centred support to people affected by dementia (people living with dementia, their family and carers) is a priority for the NHS. As our population ages, dementia is one of the most significant health and social care issues we face. The statistics presently tell us that 1 in 16 people aged 65 or over, and 1 in 6 aged 80 or over, will be affected by dementia.ⁱ Improved life expectancy means that as more people are living longer more people are developing dementia.
5. It is estimated that between 40,000 - 50,000 people in Wales are currently living with dementia.ⁱⁱ Dementia shortens life expectancy and many people will die of dementia, but also many will have other life-limiting and complex illnesses at the same time. The Office for National Statisticsⁱⁱⁱ has recently suggested that dementia is now the leading cause of death in England and Wales, with 11.6% of deaths attributable to dementia. Dementia presents a significant public health concern; overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years, are attributable to it. Dementia prevalence roughly doubles every 5 years from the age of 65 onwards.^{iv} Population projections estimate an increase of 68% in the number of people with dementia in Wales between 2011-2030 (specifically 88% for males, and 57% for females).^v Alongside this, people's health and well-being needs are becoming more complex, with many

people having multiple long-term conditions that require different levels of intervention and support.

6. As well as the human cost, it has recently been estimated that dementia costs the UK £23 billion a year.^{vi} Most of this cost, £12.4 billion per year, is met by unpaid carers, with the rest made up of social care costs (£9 billion), health care (£1.2 billion) and productivity losses (£29 million).
7. With the number of people living with dementia increasing the health and social care sector is working to provide person-centred support and services to people affected by dementia. As the draft 'Dementia Strategy' highlights, there has been significant progress and investment in dementia awareness and services, including:
 - a. Increased public awareness and support through the Dementia Friends/ Dementia Supportive Communities campaigns;
 - b. Investment in hospital settings and the community;
 - c. Increased numbers of memory clinics; and
 - d. Additional training to give NHS and social care staff the knowledge and skills to provide the best care for people living with dementia.
8. There is no doubt that Wales has the skills, the capacity and the ability to meet the demanding targets in the Welsh Government's 'Dementia Strategy'. The Welsh NHS will continue to work in partnership with social care and other public and third sectors to support people living with and affected by dementia.

Our general views on the draft 'Dementia Strategy'?

9. We welcome the development of this Strategy as a means of providing clarity over the future direction of dementia care in Wales. The draft Strategy provides a framework on which we can build on in future years. We are pleased that the Welsh Government, when drafting the Strategy, has engaged with people living with dementia, their families and carers, as well as organisations supporting people living with dementia. This engagement, and future engagement as the Welsh Government consultation develops, ensures that the focus is on what is needed to make a real difference to the lives of people affected by dementia.
10. The draft Strategy is comprehensive, especially from a prevention, health promotion, treatment and support point of view which is welcomed as it raises the profile of dementia within the health and care settings. This is important as people living with dementia constitute about a quarter of all general inpatient hospital stays, and they often have an increased length of stay due to their condition.
11. While we support and welcome the draft Strategy, we think it would benefit from more specificity regarding delivery, especially in relation to who will be delivering; what they will be delivering; and what the expected outcomes would be. The setting of key deadlines for implementation would also be beneficial to ensure delivery is accelerated in line with likely population need.
12. Given the expected increase in dementia cases in the next period, delivery of the Strategy will be heavily dependent on the Welsh Government ensuring sufficient resources are made available to both the NHS and social care to enable the development and delivery of the integrated, person-centred services designed to enable those living with dementia to live as well as possible for as long as possible. It is essential that services and resources are aligned to deliver a person-centred care approach rather than a strict medical model of care.

13. It will also be important that there is equity of access to support and services for people living with and affected by dementia, which suggests that we will need a universal set of standards to be achieved across health and social care, notwithstanding the need for more locally nuanced services in response to individual community need. This will involve consideration of environment (e.g. housing and geography) language preference, and protected characteristics.
14. Beyond these general points, we would offer the following observations:

Public health and awareness

15. We are pleased that the draft Strategy recognises the importance of healthy behaviours. It has been estimated that by promoting and adopting healthy lifestyles in middle age, an individual's risk of developing dementia could be reduced by approximately 20%.^{vii} Risk factors that may impact on the risk of dementia include: obesity, raised cholesterol levels, social isolation, smoking, alcohol and physical inactivity. An awareness raising campaign for those in middle-age, to address the lack of knowledge on dementia prevention would be advantageous. In addition, greater public awareness is required to support the general understanding about the normal ageing process, particularly with regards to memory loss, to support early advice seeking.
16. As well as public awareness campaigns, it is important that the Government and public bodies support the population to adopt healthy lifestyles, particularly in middle age. As the Welsh NHS Confederation Policy Forum 'One workforce': Ten actions to support the health and social care workforce in Wales^{viii} document highlights the *"whole workforce should be ambassadors for healthy living, making mental and physical public health and well-being a priority and working collaboratively to create the right conditions to support everyone to make healthier lifestyle choices"*. Public health plays a key role in ensuring that we reduce demand and empower people to take control of their health and well-being.
17. As part of public health and awareness we must continue to drive a mass shift in public thinking. In relation to people in poor health, the NHS and social care sectors need to communicate with people and ensure that they are aware of the choices and decisions that they are making and how they are impacting on their health and well-being. In terms of how services are used, the re-education of the public is vital and we need to support people to participate in planning, designing their care with health and social care professionals.
18. Furthermore communities need to become more dementia-aware and supportive to assist in the process of increasing diagnosis levels: this is not purely within the gift of the Health Boards.

Early intervention and diagnosis

19. We are really pleased that the draft Strategy highlights the importance of early intervention and diagnosis. Evidence clearly highlights the value of early intervention and diagnosis (including access to services, risk reduction, planning for the future and greater autonomy). Early intervention, both pharmacological and non-pharmacological, can help to slow the progress of dementia and its symptoms. It can also help to better prepare individuals and their families for the future of living with the condition. However, early diagnosis does carry ethical implications, and consideration needs to be given to ability to consent and the potential benefit and harm for each individual case.

Carers

20. We support the recognition in the draft Strategy of the crucial role of carers in supporting and caring for those living with dementia. We know that the services that carers and family members

provide are invaluable, for both those that they care for, and the public purse. The health and social care system needs to provide information and support to carers to equip them with the skills and tools they need to care for someone living with the disease. As the impact of dementia grows over the coming years, family members will have an increasingly important role to play in dementia prevention and early intervention. A key function to consider in the dementia prevention and early intervention agenda is providing support for carers. If carer breakdown occurs, or family members are not prepared for a caring role and all the life changes that are implicit with it, outcomes for individuals with dementia are inevitably worsened and usually involve admission to a care setting. Effective care giving has a major impact on the quality of life of someone living with dementia, helping them to live well and stay independent for longer. As such, investment in the skills, capacity and well-being of carers should be prioritised and seen as investing to save.

Primary Care

21. It is helpful that the draft Strategy acknowledges the need for primary care teams to understand the value of early diagnosis. In parts of the UK where a primary care led approach to dementia care has been advocated, diagnostic rates have been seen to improve significantly. A clearer expectation and responsibility for primary care to identify people who have dementia would be welcomed. While the financial incentivising of dementia diagnosis in primary care has been seen to lead to an increase in the likelihood of misdiagnosis, it would be useful to consider a mechanism to ensure that the responsibility of primary care was more explicit.

Does the Strategy covers the right areas?

The number of people diagnosed with dementia

22. There is a need to improve dementia diagnosis rates and to understand the demographic composition of the data so that we can more effectively plan to meet the current and future demand for information, support and care at the right time and in the right place. The current data regarding the number of people diagnosed with dementia needs to be more transparent, especially in relation to how diagnostic rates are calculated.
23. Currently data regarding numbers of people with dementia are collected only once a year (in March) via GP Quality and Outcomes Framework (QOF) reporting. Consequently routine monitoring of changes in diagnosis rates is challenging and Health Boards need more regular measurement to support effective service improvements locally.
24. Furthermore in relation to diagnosis rates, the method of calculating diagnostic rate presently is through comparison of age related estimated prevalence compared with the numbers of people on the primary care register. This calculation isn't always transparent via QOF. The method and methodology for calculating diagnostic rates is to be modified from the calculation achieved as a result of a Dementia Delphi Consensus Study to the dementia diagnostic rate, indicated through the Cognitive Function and Ageing Study II (CFAS II).^{ix} CFAS II only considers people who are over 65 and not those under 65 who are diagnosed with dementia. Consequently the change in the method of calculation will automatically improve diagnostic rates. It would be helpful if the algorithm for calculating diagnostic was transparent so that the diagnostic rate could be utilised in an informed way to achieve service improvement e.g. to illustrate, the Dementia Delphi Consensus Study algorithm is: 30-34yrs 0.0094%, 35-39yrs 0.0077%, 40-44yrs 0.014%, 45-49yrs 0.0304%, 50-54yrs 0.0583%, 55-59yrs 0.1368%, 60-64yrs 0.9%, 65-69yrs 1.7%, 70-74yrs 3.0%, 75-79yrs 6.0%, 80-84yrs 11.1%, 85-89yrs 18.3%, 90-94yrs 29.9%, 95yrs+ 41.1%. This would be fine if

the dementia register was split into over and under 65 so that diagnostic rate could be calculated accordingly. The register currently isn't age defined.

Supporting people in crisis

25. It is positive that the draft Strategy focuses on keeping people with dementia in their familiar home environment and preventing deterioration where possible. It also recommends that NHS organisations have teams and resources dedicated to managing people with dementia in the community, which is likely to mean a realignment of existing resources to support new models of care and health and social care-wide system support for dementia patients and their carers/families.
26. The Strategy also needs to recognise what is needed to manage crisis situations, which is when the Welsh Ambulance Service NHS Trust (WAST) is most likely to receive a 999 call. Individuals with dementia do not benefit from being taken to a busy Emergency Department and it is important that the health and care system has pathways in place (preferably 24/7) so that community assessment and ongoing management services are available and responsive.
27. The role of Unscheduled Care Services could be strengthened in this strategic direction. Given developments within WAST, the changing role of their clinical staff and the changing nature of their case mix, it is important that the contribution of WAST is reflected in the Strategy.

Implementation

28. The key actions within the draft Strategy are in some places not directed. Some of the proposed actions could be more explicit, for example '*increase the number of primary care practices in Wales that are dementia supportive*' on p 20 of the draft Strategy. To demonstrate this it might be helpful to identify the percentage of practices, where staff have received an appropriate level of awareness /training and efforts have been made to provide a dementia friendly service and environment. Health Boards will need to build on this year on year with expectation of eventual 100% compliance. The 'Good Work: A Dementia Learning and Development Framework for Wales'^x will be instrumental in achieving this cultural shift.

Specific areas where the chapters within the Strategy could be improved

29. As well as the specific areas highlighted by Public Health Wales NHS Trust in their written response to the Committee, which we support, the following areas could improve the Strategy:

a. The title

30. The current title of the Strategy may need to be revised to describe it as a 'Dementia' Strategy. The reference to 'friendly Wales' confuses the overarching nature of the Strategy with the more specific elements focused on Dementia Friendly Communities.

b. Introduction

31. Page 12 states that "*£130m to be invested in new older persons mental health facilities and £500,000 a year for Occupational Therapy Support Workers to be in every older person's mental health ward in Wales*". We would ask that consideration should be given to the fact that the vast majority of people living with dementia are treated within the acute hospital setting. The issues is whether this money (£130m and £500k) would be more prudently invested in improving environments and activity participation for those wards located in the acute settings.

32. In addition, it is unclear from the Strategy what is required to ensure that general health services are dementia aware and friendly and how can the NHS build this into their estates design and facilities provision.

c. Risk reduction and health promotion

33. In relation to page 20 a clear working definition is needed of what constitutes a 'suitably competent clinician' in terms of the diagnostic process. The Strategy should clarify that an official and *registered* diagnosis is needed to enable individuals and families/carers to access post diagnostic services.
34. In relation to memory clinics, referrals to memory clinics should not be the sole reserve of Doctors, GPs and Consultants. Referrals should be open to other qualified health professionals such as Nurses, Occupational Therapists and Physiotherapists. The current system causes extended delays in securing memory clinic appointments. To counteract the argument that this will lead to a huge number of inappropriate referrals, clinics should consider developing robust triage processes. Furthermore we would recommend the addition of the utilisation of 'Making Every Contact Count' within NHS healthcare settings by all staff with patients in the Strategy.

d. Recognition and Identification

35. Regional integrated 'dementia pathways', jointly developed and owned by health and social care, would be helpful in describing what support and services should look like across the range of services and would assist in driving up best practice. This could support in determining regional performance measures and in identifying local solutions to local difficulties. This may also support stakeholder involvement, particularly in the development of dementia friendly communities and helpful in signposting to appropriate services.

e. Assessment and diagnosis

36. While we are supportive of the annual targets set out on page 51 of the draft Strategy, it has not been made explicit within the draft Strategy that a diagnosis percentage of 51% (compared with those expected to have the condition) is the lowest percentage in the UK, far lower than Northern Ireland and Scotland (c 90%). Subsequently there should be a commitment to specific annual targets to improve the percentage of case identification and diagnosis. To achieve this additional resources to Memory Clinics will be needed to ensure dementia is diagnosed in a timely manner.
37. As highlighted in the previous page, there needs to be a greater emphasis within this section of the Strategy on the role that all health professionals (GPs, pharmacists, general hospital staff, geriatricians and physicians etc) must play in diagnosing, treating, monitoring and caring for people with dementia. There is also an opportunity to establish an explicit recommendation to establish a diagnostic pathway as a feature of acute hospital admission initiated by cognitive screening and the elimination of delirium diagnosis, which is already in place in England. Alongside this there needs to be clear recognition of the need to increase and expand the availability of, and access to, both Memory Service specialist dementia services and the number of consultant of Old Age psychiatrists across Wales.

f. Living as well as possible for as long as possible with dementia

38. There needs to be more clarity within the Strategy in regards to meeting the challenge of providing equitable support to all people living with and affected by dementia irrespective of where they live, what language they speak and whether they have protected characteristics. The draft Strategy does not clearly state how the challenge of supporting people with dementia in a rural community will be met. Specifically who will explore the options around telehealth, telecare and assistive technology and ensure access to Occupational Therapy? Nor does it explain how the

needs of Welsh speakers will be met. In addition the Strategy would benefit from consideration of the extra resources that may be required for people with sensory loss, BAME communities and LGBT+. Support for carers also needs to include consideration of same sex couples, who are often disadvantaged and disempowered.

39. It would be helpful if the Strategy gave greater consideration to the impact of environment, including housing, education and employment as well as that potential for reablement services to support the person with dementia to establish compensatory strategies. Addressing environmental factors and providing access to reablement services supports people to carry out essential daily living activities for longer. In this context it would be appropriate to include a recommendation that this type of service was available as part of the key actions.
40. The action within the Strategy that a *“reduction in the percentage of people with a diagnosis of dementia receiving inappropriate anti-psychotic medications and a reduction in duration, particularly in care homes”* is welcomed. However, it does not go far enough in terms of Welsh Government support. To optimise this firstly Care and Social Services Inspectorate Wales (CSSIW) could be engaged in ensuring that non-pharmacological methods should be used where possible in care homes for behaviour that challenges staff and secondly, further resource could be invested in the data extraction and education of GP practices in anti-psychotic prescribing where needed.
41. This Strategy should make the connection to other Welsh Government Strategies that relate to the treatment and care of people with chronic conditions and also sensory impairment as the demographics around this are clear.

g. The need for increased support in the community

42. In relation to the ‘In the More Specialised Care and Support’ section it almost entirely refers to Community Mental Health Teams (CMHTs) as the teams responsible for offering support. This is directly at odds with the fact that dementia is not a mental health condition and is a physical disease. It is felt that this section contradicts that view, we feel that all community teams should have the skills required to provide support to people living with dementia and who regularly come into professional contact with people living with dementia. Many CMHTs are not multidisciplinary and do not have specialist skills to deal with needs of people living with dementia. Should this area of work be seen as the responsibility of CMHTs we feel that individuals may be referred onto these services which could very quickly be overwhelmed. We would suggest that if staff need to be trained and educated in line with the ‘Good Work – Training Framework’, then all community staff will have the skills to provide timely, evidenced based care whatever the clinical setting.
43. Within the End of Life Care section of the Strategy there is a need to clearly define the difference between ‘Palliative Care’ and ‘End of Life Care’ because these terms are not interchangeable. ‘Palliative Care at End of Life’ is a different definition again. Palliative Care is a process that should commence at a point after diagnosis that enables forward planning and discussion around Advanced Care Plans, Power of Attorney and Advanced Directives. Palliative Care practices should accept that dementia is a progressive disease that will ultimately lead to End of Life. End of Life Care should be defined as a process that occurs when people are actively dying. If the Palliative Care process has been stringent and efficient, it should inform decision making when that person is entering their last days of life. Without considering the need for Palliative Care post diagnosis there is a distinct likelihood that decisions made at End of Life could be made from a crisis management perspective, many official reports have shown that such an approach leads to a distressing end of life experience for people.

44. We would recommend a specific emphasis within the Strategy on utilisation of the Intermediate Care Fund to support people living with dementia.
45. Finally, it is also important that people living with dementia have all of their drugs reviewed regularly. It must also be remembered that in some cases the clinical view is that medication to relieve severe anxiety may be in a person's best interests, but this must be part of a regularly reviewed clinical care plan.

h. Supporting the Plan

46. In relation to training, while some specialist training is required, this generally involves enhancing the skills for those providing personal care and treatment and may apply equally to carers at home as staff in a hospital or other care settings. What is important is ensuring the right care approach is provided depending on what the individual requires and that this is understood and communicated to others so that this is delivered with the skills and consistency to avoid distress and agitation. Another key issue relating to training that needs to be considered is that there is no reference around the need for staff to receive regular specialist training in how to reduce distress and aggression in older people's services generally, and inpatient services & nursing homes specifically. Dementia services consistently have the highest incidence of aggressive incidents of any clinical population and there is a wealth of clinical evidence about reducing challenging behaviour in dementia that is specific to this condition.
47. With regard to research within the Strategy, the International Consortium for Health Outcomes Measurement (ICHOM) work is worth referencing. This brings together patient representative, clinician leaders and relevant others from across the globe to develop standard sets focussing on patient outcomes and quality of life.

Conclusion

48. As highlighted in our response to the inquiry providing person-centred support to people living with dementia is a priority for the NHS. There is significant work already being done across the health and social care sector to support people affected by dementia but this Strategy provides further clarity over the future direction of dementia care in Wales.

ⁱ Alzheimer's Society, November 2014. Key stats on older people, ageing and Age UK.

ⁱⁱ Welsh Government/ Statics for Wales, October 2016. General Medical Services contract: Quality and Outcomes Framework statistics for Wales, 2015-16

ⁱⁱⁱ Office for National Statistics, November 2016. Deaths registered in England and Wales (Series DR): 2015

^{iv} Williams J W, Plassman B L, Burke J, Holsinger T, Benjamin S. 2010. Preventing Alzheimer's Disease and Cognitive Decline. Report No.: Number 193.

^v Public Health Wales, August 2010. Public Health Wales Future Dementia Estimates (2011). 11 A.D. Aug 23.

^{vi} Luengo-Fernandez R, Leal J, Gray A. Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom.

^{vii} Russ T C, Starr J M. Clinical Evidence Editorial : Could early intervention be the key in preventing dementia? BMJ Group.

^{viii} Welsh NHS Confederation Policy Forum, September 2016. 'One workforce': Ten actions to support the health and social care workforce in Wales.

^{ix} Cognitive Function and Ageing Study <http://www.cfes.ac.uk/cfas-ii/>

^x Care Council for Wales, NHS Wales, Public Health Wales and the Welsh Government, November 2016. Good Work: A Dementia Learning and Development Framework for Wales

Agenda Item 7

Yng Gynghraeth y Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-04-17 Papur 3 / Paper 3



ADSS Cymru

Leading Social Services in Wales

Yn arwain Gwasanaethau

Cymdeithasol yng Nghymru



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.

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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.

Comisiynydd Plant Cymru
Children's Commissioner for Wales
Sally Holland

Dr Dai Lloyd AM
Chair, Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

17 January 2017

Dear Dr Lloyd

Public Health (Wales) Bill

Thank you for your letter dated 12th January and your request for further information about my evidence on the provisions in the Public Health (Wales) Bill relating to age restrictions for intimate piercings.

In considering my response to provisions around the proposed age restrictions for intimate piercings, much internal debate was prompted within my office around the delicate balance to be maintained between the voice of the child, including ability to consent and protection of children and young people. Government, practitioners and services working with children and young people are duty bound to act in the child's best interests (UNCRC article 3) and there is a fine line to determining the most appropriate age for the restriction of intimate piercings.

In my initial evidence, I tentatively agreed with the introduction of a prohibition on the intimate piercing of persons under the age of 16 years, aligning with Welsh Government's guidance in relation to consent for medical treatment in which 16 and 17 years olds have the ability to consent to medical treatment without the need for their parent's permission. I did, however, confirm that it is important to recognise there are still safeguarding considerations to be addressed in relation to the intimate piercing of young people aged 16 and 17 in relation to their health, safety and welfare.

I have reviewed the stage 1 evidence of the Royal College of Physicians, the Directors of Public Protection Wales and the Chartered Institute of Environmental Health, I recognise the validity of these experts' arguments raised for a higher age restriction in relation to vulnerability of an individual, ability to consent, coercive control, and permanent scarring or damage. I am particularly interested in concerns expressed around potential links to Child Sexual Exploitation, risky behaviours experiences which may lead children to considering an intimate piercing around the age of 16. I would be keen to see further expansion and consideration of information and evidence in this area to inform the development of the Bill moving forward.

Yours sincerely





Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: MA-L/RE/0023/17

Dr Dai Lloyd AM
Chair of the Health, Social Care and Sport Committee
National Assembly for Wales
Ty Hywel,
Cardiff Bay
Cardiff
CF99 1NA

18 January 2017

Dear Dai,

Public Health (Wales) Bill

I would like to thank you and the committee for the opportunity to discuss the Public Health (Wales) Bill on 11 January 2017 and for your follow-up letter of 12 January 2017.

I have been giving careful consideration to the evidence the committee has received during Stage 1, including the evidence you refer to in your letter. The specific issues raised in your letter relating to intimate piercing and the relevant offences under the proposed special procedures licensing system require detailed consideration. I therefore intend to write to the committee with further information about these points once I have had an opportunity to explore all the relevant issues in detail.

In the interim, I enclose a copy of the letter I sent to BMA Cymru Wales on 21 December 2016, following their evidence to the committee. In the letter, I have confirmed I am happy to reiterate the assurances, which were provided by the previous Health Minister when the Bill was considered by the Fourth Assembly. I have also confirmed the previous amendments to the provisions about pharmaceutical needs assessments, which were made in response to the BMA's concerns have been retained in the Bill.

Kind regards

Rebecca Evans AC / AM

Y Gweinidog Iechyd y Cyhoedd a Gwasanaethau Cymdeithasol
Minister for Social Services and Public Health

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Rebecca Evans AC/AM
Gweinidog Iechyd y Cyhoedd a Gwasanaethau
Cymdeithasol
Minister for Social Services and Public Health



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref MA-L/RE/5436-16

Keith Ward
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21 December 2016

Dear Keith,

During the evidence provided on behalf of BMA Cymru Wales by Dr. Phil Banfield and Dr. Stephen Monaghan at the Health, Social Care and Sport Committee's evidence session on the Public Health (Wales) Bill on 15 December, I was asked to provide certain assurances in relation to pharmaceutical needs assessments.

I can confirm that I am content to reiterate the assurances which were provided when the Bill was considered by the previous Assembly. These are also consistent with amendments made to the Bill during the previous scrutiny process, which have been retained.

The specific detail of how pharmaceutical needs assessments will be conducted will be set out in regulations following the passage of the Bill. We will consult on those regulations but I am happy to give an indication now that I expect pharmaceutical needs assessments to reflect consideration of the contribution of all providers in addressing local health needs. That would clearly include the contribution of dispensing doctors. I would be pleased for GPC Wales to contribute to these discussions and I have asked my officials to ensure you are involved at the appropriate stage as a key stakeholder.

Kind regards

Rebecca Evans AC/AM
Gweinidog Iechyd y Cyhoedd a Gwasanaethau Cymdeithasol
Minister for Social Services and Public Health

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.



Consultation on the Public Health (Wales) Bill

RCP Wales further written evidence

About us

The Royal College of Physicians (RCP) aims to improve patient care and reduce illness, in the UK and across the globe. We are patient centred and clinically led. Our 33,000 members worldwide, including 1,200 in Wales, work in hospitals and the community across 30 different medical specialties, diagnosing and treating millions of patients with a huge range of medical conditions.

The Faculty of Forensic and Legal Medicine (FFLM) is a standard setting body that is involved in recommending the educational needs of doctors working in forensic and legal medicine.

Amdanom ni

Mae Coleg Brenhinol y Meddygon yn amcanu at wella gofal cleifion a lleihau salwch, yn y DU ac yn fyd-eang. Rydym yn sefydliad sy'n canolbwyntio ar y claf ac sy'n cael ei arwain yn glinigol. Mae ein 33,000 o aelodau o gwmpas y byd, gan gynnwys 1,200 yng Nghymru, yn gweithio mewn ysbytai a chymunedau mewn 30 o wahanol feysydd meddygol arbenigol, gan ddiagnosio a thrin miliynau o gleifion sydd ag amrywiaeth enfawr o gyflyrau meddygol.

For more information, please contact:

Lowri Jackson

RCP senior policy and public affairs adviser for Wales

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20 January 2017

From the RCP vice president for Wales
O'r is-lywydd yr RCP dros Gymru
Dr Gareth Llewelyn FRCP
Gareth.Llewelyn@rcplondon.ac.uk

From the RCP registrar
O'r cofrestrydd yr RCP
Dr Andrew Goddard FRCP
Andrew.Goddard@rcplondon.ac.uk

Consultation on the Public Health (Wales) Bill

Further to the RCP's oral evidence to the Health, Social Care and Sport Committee on 11 January 2017, please find below additional evidence, especially on our recommendation that the age of consent for intimate piercing contained within this Bill be raised to 18 in line with the Tattooing of Minors Act 1969.

- Genital piercing is considered in under 18 year olds to be type 4 female genital mutilation (FGM) and [therefore a criminally reportable event](#). This came into place at the end of 2015.
- In many developed countries, including Australia, New Zealand and most US states, intimate piercing of minors (those under 18 years old) is considered a criminal offence.
- Good practice in the piercing community will not carry out intimate piercing with those under 18 years old. Some even restrict it to those over 21, as they view it as a safeguarding issue.

You may also find this [Tattooing and body piercing guidance toolkit](#) from the Chartered Institute of Environmental Health helpful.

More information about our policy and research work in Wales can be found [on our website](#). Alternatively, please contact Lowri Jackson, RCP senior policy and public affairs adviser for Wales, at Lowri.Jackson@rcplondon.ac.uk with any questions.

With best wishes,

Dr Olwen Williams
RCP Wales public health officer
Swyddog iechyd cyhoeddus yr RCP Cymru

Dr Gareth Llewelyn
RCP vice president for Wales
Is-lywydd yr RCP dros Gymru

Dr Andrew Goddard
RCP registrar
Cofrestrydd yr RCP

Dr Dai Lloyd AM
Chair
Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

25th January 2017

Dear Dr Lloyd,

PUBLIC HEALTH (WALES) BILL

I wanted to thank you again for the chance to give evidence in front of the Committee last week on the Public Health (Wales) Bill. It was a fantastic opportunity for the charity and for me personally so thanks again.

I know the Committee will soon be drafting their recommendations on the Public Health (Wales) Bill so I wanted to clarify and expand, for members' consideration, on two issues which I discussed when giving evidence. These are on a Statutory Duty and Government Oversight.

A Statutory Duty to Ensure Access to Toilets

Many organisations have joined Crohn's and Colitis UK to state that the Bill needs strengthening to ensure the primary objectives of Part 7 are met. A way of doing this would be for the Committee to recommend the introduction of a statutory duty to ensure access to toilets. The reason why Crohn's and Colitis UK advocate for a "duty to ensure access" rather than a "duty to provide public toilets" is that we recognise that in the future, toilet supply may come from a variety of sources and not necessarily from traditional public toilets, even though this would always be our favoured position.

What lies behind the calls for such a statutory duty is the need for local authorities to actually deliver on the conclusions of their local toilets strategies, rather than the strategy becoming a theoretical document which delivers little to improve public health. In practice, whether this is a specific duty that is needed within the Bill or simply amendments that give effect to supporting implementation, this is not as important as the end itself, which is to increase access to toilets.

Giving greater weight to the implementation of the local strategies in increasing access to toilets may only require very small amendments to the current Bill. For example under its previous guise, Amendments 104 and 105 (copies attached) were submitted with cross party support and these proposed small changes which would strengthen the delivery aspect of the local toilets strategies.

Crohn's and Colitis UK would support similar amendments. One suggestion would be an amendment to Section 110, page 65, line 31 which would alter one word in this sentence from "proposes to deliver" to "will deliver". This would give greater effect to delivering on the conclusions of the local toilets strategies and, in practice, achieve the aims of a statutory duty to ensure access to toilets.

Government Oversight

The Government has recognised that the supply of toilets across Wales is of serious concern and by adding Part 7 to the Bill, the Government has shown considerable leadership in treating access to toilets as a public health issue for the very first time.

However, we are concerned that the Government's solutions to this public health concern weighs solely on local authorities, with no role for the Government other than providing statutory guidance.

It is our contention that to fully address the public health concerns identified, the Government has a significant role to play in not only ensuring a One Wales approach to access to information through a toilet app, but for this to be supported through a duty on the Government to provide a review and oversight function across Wales to all 22 local toilets strategies.

This would not only support the delivery of the recommendations of local toilets strategies but would provide cross-Wales analytics allowing the Government to report on the success of this part of the Bill and its ability to improve public health across Wales. This would be of considerable use in strengthening the Bill and achieving its main aims, without being cost prohibitive.

Thank you again for your time and we hope that the Committee will give serious consideration to these proposals.

With best wishes



Andy McGuinness
Social Policy and Public Affairs Officer
Crohn's and Colitis UK

HYSBYSIAD YNGHYLCH GWELLIANNAU NOTICE OF AMENDMENTS

Cyflwynwyd ar 14 Rhagfyr 2015
Tabled on 14 December 2015

Bil Iechyd y Cyhoedd (Cymru) Public Health (Wales) Bill

Mae'r gwelliannau â * ar eu pwys yn rhai newydd neu'n rhai sydd wedi'u haddasu
Amendments marked * are new or have been altered

***Darren Millar**

104

Gyda chefnogaeth / Supported by: Lindsay Whittle, Kirsty Williams

Section 91, page 52, line 10, leave out 'an' and insert 'a fair and reasonable'.

Adran 91, tudalen 52, llinell 10, ar ôl 'asesiad', mewnosoder 'teg a rhesymol'.

***Darren Millar**

105

Gyda chefnogaeth / Supported by: Lindsay Whittle, Kirsty Williams

Section 91, page 52, line 12, leave out 'setting out the steps which the local authority proposes to take to meet that need' and insert 'specifying how the local authority will address that need in an effective way, including the timescale for doing so'.

Adran 91, tudalen 52, llinell 12, hepgorer 'nodi'r camau y mae'r awdurdod lleol yn bwriadu eu cymryd i ddiwallu'r angen hwnnw' a mewnosoder 'pennu sut y bydd yr awdurdod lleol yn mynd i'r afael â'r angen hwnnw mewn ffordd effeithiol, gan gynnwys yr amserlen ar gyfer gwneud hynny'.



***Darren Millar**

106

Gyda chefnogaeth / Supported by: Lindsay Whittle, Kirsty Williams

Section 91, page 52, after line 14, insert –

- ‘() The timescale specified under subsection 2(b) must be a reasonable timescale having regard to the circumstances.
- () A local authority must implement its local toilets strategy in full within the timescale specified in the strategy.’.

Adran 91, tudalen 52, ar ôl llinell 14, mewnosoder –

- ‘() Rhaid i’r amserlen a bennir o dan is-adran 2(b) fod yn amserlen resymol sy’n rhoi sylw i’r amgylchiadau.
- () Rhaid i awdurdod lleol roi ei strategaeth toiledau lleol ar waith yn llawn o fewn yr amserlen a bennir yn y strategaeth.’.

***Darren Millar**

107

Gyda chefnogaeth / Supported by: Lindsay Whittle, Kirsty Williams

Section 91, page 52, after line 32, insert –

- ‘() implementing a local toilets strategy,’.

Adran 91, tudalen 52, ar ôl llinell 32, mewnosoder –

- ‘() rhoi strategaeth toiledau lleol ar waith,’.

