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Meri Huws Comisiynydd y Gymraeg Welsh Language Commissioner





Dai Lloyd AM Chair Health, Social Care and Sport Committee National Assembly for Wales

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05/11/18

Dear Dai Lloyd AM

Welsh Speakers' Dementia Care

Over the last year the Welsh Language Commissioner and Alzheimer's Society Cymru have been working on a project looking at the experiences of Welsh speakers of dementia care, information and support services. The report will be launched on 7 November in the Assembly and we thank you as an Assembly Member for sponsoring the event. I attach a copy for your attention. It will also be available on the websites of the Welsh Language Commissioner and Alzheimer's Society Cymru from 7 November onwards.

There is a general recognition that offering services in Welsh is a clinical need for Welsh speakers with dementia. Although there are examples of good practise the report highlights failures in the care that Welsh speakers receive that can be detrimental to them. At an all Wales level, therefore, it appears that dementia care for Welsh speakers is inadequate. This is unacceptable. There are doubts as to the extent to which the active offer has developed from being a policy concept in strategies such as *More than just words...* to a reality which reflects a genuine understanding of the practical meaning of the concept. In the same way the findings of the report suggest that requirements made in relevant legislation such as the Social Services and Well-being (Wales) Act 2014 are not being fully implemented in relation to the Welsh language.

The report also highlights inconsistencies in the range of tools, diagnostic tests and assessment resources available and used with Welsh speakers that can affect the care that they receive. The need to collect data in order to plan services and train the workforce to offer care in Welsh

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was also apparent. The report makes several recommendations to the Welsh Government and other relevant bodies that include:

- That the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care packages of people with dementia and of leaders in the field.
- That the Welsh Government, in implementing the Dementia Action Plan for Wales considers the extent to which the relevant targets set for health and social care services in More than just words have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision.
- The need for the Welsh Government to integrate the Welsh language more closely into the Dementia Action Plan for Wales such as by ensuring that the Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia; setting up a similar post or responsibility with regards to the clinical needs of Welsh speakers; that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual; and that a specific action plan is developed to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams
- That the Welsh Government should set up a Welsh medium dementia care pathway and cooperate to develop a national platform to share tests, resources, expertise and information about dementia and the Welsh language.

The report also asks the Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it' is being met in relation to dementia care, and specifically, the consideration given to the Welsh language in assessments; commissioning and delivering care; individual care plans, and how local authorities and Local Health Boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

We would be very grateful if you could consider the findings and recommendations of this report especially the recommendation that is made to the Health, Social Care and Sport Committee. You are welcome to contact Huw Owen, Huw.Owen@alzheimers.org.uk to arrange a meeting if you wish to discuss the report further. We will also be setting up an implementation group which will include members from the Royal College of Nursing, Royal College of Practitioners, Royal College of Psychiatrists and other relevant organisations from the fields of health and social care to support the work of implementing the recommendations.





We look forward to discussing the report with you further,

Meri Huws

Welsh Language Commissioner

Sue Phelps

Sisdal

Wales Director, Alzheimer's Society Wales

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Foreword

If care is not available in Welsh, there is a shortcoming in that care. Welsh language provision is an important part of people's health and care package, whatever their age or need. It is even more important for children, vulnerable individuals and people living with dementia.

I have heard the stories, experiences and evidence of dozens of people affected by dementia who have been unable to receive care through the medium of Welsh. Hearing these stories, it became clear to me that each individual case is not an exception, and that there are examples of inadequate provision across the country. With an ageing population and forecasts that the number of people living with dementia will increase significantly over the next decades, robust and urgent action must be taken to ensure that Welsh-medium provision is available to meet the need. That was the impetus of this partnership with Alzheimer's Society Cymru.

From the initial diagnosis to the dealings with various professionals, not offering a service in the language most natural to an individual can lead to delays and shortcomings in the planning and delivery of appropriate care. As dementia is a condition which affects linguistic ability, people are at risk of losing grasp of their second language, and not providing care in the Welsh language can lead to frustration and to losing dignity and respect.

Today, there are more laws, policies and strategies than ever before which recognise the importance of providing services and care through the medium of Welsh. The recommendations in this report concentrate on putting the principles into action and ensuring that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

Meri HuwsWelsh Language Commissioner



Foreword

We estimate that there are currently 45,000 people living with dementia in Wales. Every single person in Wales living with dementia, regardless of a formal diagnosis, has the right to live well with dementia. What living well means varies from person to person, but what is not in doubt is that for a large amount of people across Wales, that means being able to access services, receive care, and deal with medical professionals in their first language, Welsh.

As the *Dementia Action Plan* states "For Welsh speakers living with dementia, receiving care and support in their first or preferred language is a matter of clinical need." The Welsh Government also committed to strengthening the active offer with the Welsh language standards coming in for the sector in 2019.

Whilst these commitments by the Welsh Government are to be welcomed as a step in the right direction, we need to ensure that we turn them into action to deliver on the principles and rights stated in the *Dementia Action Plan* to ensure that we can provide the highest quality service, and ensure that everyone can live well with dementia.

We hope that this report, and the recommendations contained within will not only provide impetus to the Government to drive forward their changes to Welsh language care, but to practitioners across all medical fields, and the social care sector, to ensure that the people they work with on a daily basis are supported to live well in the language they choose.

The time to act on this is now. Together, we can make Wales a dementia friendly nation.

Sue PhelpsDirector, Alzheimer's Society Cymru



1. Introduction

- 1.1 One of the strategic aims of the Welsh Language Commissioner is to influence the consideration given to the Welsh language in policy development. From the outset, the Commissioner has identified health and social care as a key area in relation to the Welsh language and the needs of Welsh speakers. The Welsh language in primary healthcare services was the subject of the Welsh Language Commissioner's first inquiry, *My Language*, *My Health*, published in 2014.² This report builds on that work.
- 1.2 Alzheimer's Society is the UK's leading dementia charity. It provides information and support to people with dementia and their carers and funds research in order to create permanent change for people affected by dementia.³ Alzheimer's Society Cymru strongly believes that a Welsh language service should be delivered to those who need it for clinical reasons as it affects their health and well-being outcomes.
- In light of this, the Welsh Language Commissioner and 1.3 Alzheimer's Society Cymru have collaborated on a project focussing on the Welsh language and dementia. The research company Wavehill was commissioned to undertake a study of the care and support services delivered to Welsh speakers with dementia. This qualitative research involved consultation with senior officers from local authorities and health boards; academics in the field; care and support providers; and people living with dementia. The purpose of the study was to investigate the main factors and themes influencing the provision, or lack of provision, of Welsh medium dementia health and support services, and learn about the experience of Welsh speakers with dementia of that provision. A round-table event was held with experts in the field to discuss the findings of the research and offer possible policy solutions in response to the difficulties identified.
- 1.4 This document summarises the findings of the project. Firstly, it outlines the nature of dementia and highlights the relevant language considerations. It then discusses the policy and legislative developments that are relevant to the field. We then present the findings of our research and the experiences of those living with dementia of the Welsh medium care available to them. Finally, it highlights the difficulties identified and the policy solutions which could, if adopted, make a positive difference to the provision for Welsh speakers.

Welsh Language Commissioner, My Language, My Health: The Welsh Language Commissioner's Inquiry into the Welsh language in Primary Care http://www.comisiynyddygymraeg.cymru/English/ Publications%20List/Health%20inquiry%20full%20report.pdf [accessed 6 September 2018]

^{3.} This may include a person with dementia, unpaid carers, family, friends and the wider support network.

Recommendations

Recommendation 1

We ask the Assembly's Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it' is being met in relation to dementia care. Specifically, the consideration given to the Welsh language in the following areas should be examined:

- Assessments
- Commissioning and delivering care
- Individual care plans
- How local authorities and local health boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

Recommendation 2

We recommend that Care Inspectorate Wales and the Healthcare Inspectorate Wales recognise that a lack of care in the Welsh language for those who require it constitutes poor care which may have a harmful effect on people. The ability of providers to offer care in Welsh to people with dementia should constitute good practice and be a measure of the quality and safety of services. This should form part of their inspection work.

Recommendation 3

We ask the Welsh Government, in implementing the *Dementia Action Plan for Wales*, to consider the extent to which the relevant targets set for health and social care services in *More than just words* have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision. If they have not been met, steps should be taken to rectify this in order to facilitate implementation of the Action Plan and other recommendations made in this report.

Recommendation 4

We ask local authorities, health boards and the Welsh Government to work together to develop a Welsh language care pathway. This is a golden opportunity to ensure that the Welsh language is central to individuals' care pathways and that staff working with them and their families can respond to their language needs.

Recommendation 5

We ask the Welsh Government to produce a specific action plan to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams which form part of the Action Plan, in order to ensure that the care commitments made in the Social Services and Well-being (Wales) Act 2014 are fulfilled.

Recommendation 6

As part of the commitment above to undertake further work on dementia assessment tools we ask the Welsh Government to work with local authorities and health boards in Wales to develop a national platform to share Welsh language tests as well as resources, expertise and information about dementia and the Welsh language. This will ensure that they are recognised by the different professions working with people with dementia and raise awareness of them amongst health and social care workers.

Recommendation 7

We ask the Welsh Government along with health boards and local authorities to develop national and local forums to share experiences of delivering care and volunteering in Welsh which would contribute experiences and information to the national platform mentioned above.

Recommendation 8

We ask the Welsh Government to put technology in place to ensure that information about patients' language choice and needs is recorded and that this information is transferred effectively between health and social care services.

Recommendation 9

We ask the Welsh Government to ensure that the new Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia. This can include raising awareness of the importance of the active offer, in order to drive service improvement and raise awareness of the importance of the language of provision when delivering dementia care.

Recommendation 10

We ask the Welsh Government to ensure that the equivalent responsibility or post to the All Wales Dementia Allied Health Practitioner is created in the clinical field in order to provide clinical advice and leadership and support in relation to dementia and the Welsh language to health boards, local authorities, health professions and others, and to raise awareness of the importance of the language of provision and the active offer when delivering dementia care. This national leader could be responsible for developing the platform and national forums in recommendations 6 and 7 also.

Recommendation 11

We ask that the commitments made in *More than just words* relating to collecting data about the linguistic needs of the public and the language skills of the workforce be implemented fully and promptly in relation to delivering dementia services. Based on this information Health Education and Improvement Wales should cooperate and strategically plan with higher and further education establishments, the Coleg Cymraeg Cenedlaethol and health boards to commission places for Welsh speakers on relevant training courses and ensure that Welsh speakers are aware of the need for Welsh speaking health and social care workers and the opportunities open to them.

Recommendation 12

We recommend that Health Education and Improvement Wales should ensure that language awareness, an understanding of the impact of dementia on bilingual people; the fact that offering health and social care provision in Welsh is a clinical need for a number of Welsh speakers; the rights of Welsh speakers to receive services in Welsh, and the importance of the active offer are an integral part of the education and training of all health service professionals across Wales. This should be part of the initial training of health workers and part of their continuing professional development, and especially part of the training of leaders in these fields.

Recommendation 13

We recommend that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual as part of the *Dementia Action Plan*.

Recommendation 14

We recommend that the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care package of people with dementia and of leaders in the field. Based on this audit, plans should be made to raise awareness of these matters amongst these workers, e.g. by undertaking a specific campaign to raise awareness of dementia and the active offer.

Recommendation 15

As part of the *Dementia Action Plan for Wales* and in light of the requirements that are and will be applicable to them in accordance with the Welsh language standards, health boards and local authorities should ensure that specialist Welsh learning provision is available for workers involved in the care package for people living with dementia, using the plans offered by the National Centre for Learning Welsh for example. Also, where possible, relevant health and social care workers from all professions should be released for extended periods to develop language skills that will enable them to provide care through the medium of Welsh.

Part 1 Setting the context

Overview of this section

- The effects of dementia are progressive and people experience different stages.
- People living with dementia deal with a number of different professionals and therefore the Welsh language provision offered by all services needs to be considered.
- Dementia is a condition which affects people's linguistic ability and there is evidence, from Wales and beyond, which shows that bilingual people are at risk of losing grasp of their second language.
- Failure to deliver services in the most appropriate language can lead to delay in diagnosing dementia and shortcomings in the planning and delivery of care to Welsh speakers with dementia.
- Delivering services in the language which feels natural to people living with dementia is a basic clinical need and this is recognised in Welsh Government policy.
- Legislation places a duty on authorities to consider the Welsh language in assessing, commissioning and delivering care to individuals in order to ensure that they experience the best possible outcomes.

1. Dementia and the dementia care pathway

- 1.1 Dementia can include several different conditions including Alzheimer's, vascular dementia and dementia with Lewy bodies. People with dementia can develop a number of different symptoms including memory loss; difficulty in solving problems and language difficulties. Dementia is a progressive condition and is often described as a series of steps on a journey which reveals new symptoms.
- 1.2 People living with dementia will come into contact with many different professionals and services on their journey. A detailed explanation can be found on Alzheimer's Society's website. The first point of contact will often be the GP. Sometimes, the GP or a specialist nurse may be able to make the diagnosis themselves, depending on their expertise and training. More often, people are referred to a memory clinic or another specialist service for assessment and diagnosis. Professionals delivering this service can include psychiatrists, clinical psychologists, specialist clinical nurses, geriatricians or neurologists and assessments range from discussing the individual's history (how their symptoms have developed), physical tests (e.g. blood tests), cognitive tests and a brain scan.
- 1.3 After diagnosis, the next step is to undertake an assessment of care needs. Local authority social services departments have a duty to undertake this assessment.⁵ See section 2 for more information about this. The assessment includes a number of questions, often in the form of a discussion, to determine the individual's needs and the type of support that they require. The assessment will normally involve a face to face discussion in the individual's home undertaken by a social worker from the local authority.
- 1.4 Then, the local authority will decide whether the individual is eligible to receive funding for their care needs. Subsequently, the individual can receive advice and support from a dementia support worker and the opportunity to discuss their diagnosis with a health or social care professional. This may include a psychiatrist or a mental health nurse, a clinical psychologist, an occupational therapist or a GP.

https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia/6 [accessed 4 September 2018]

https://www.alzheimers.org.uk/info/20032/legal_and_financial/35/assessment_for_care_and_support_ in_wales/3 [accessed 4 September 2018]

- 1.5 The next step, after the needs assessment, is to develop a Care and Support Plan for the individual setting out how their needs should be met.⁶ The plan may state that the individual is independent enough to live at home but requires regular visits from a social worker, for example, to assist with eating, washing and so on. The plan may note that a day care centre would be the most suitable support provider and, once the condition progresses to a specific stage, it is possible that the individual may need continuous support and live in a care home. Support will either be delivered directly by the local authority; or the authority will arrange for another organisation (e.g. from the private sector) to deliver the service; or the authority may make a payment to the individual or their carer to arrange their own care and support.
- 1.6 Around 60% of people receiving domiciliary care in Britain are living with dementia, and around 70% of people living in care homes have dementia.⁷ According to a report by Alzheimer's Society in 2007, a third of people with dementia live in care homes and therefore, the vast majority live in the community.8 As mentioned above, people living in the community can receive a range of different services including respite care, visits to day care centres, participation in a wide range of activities etc. In terms of care homes, there are two main types - nursing and residential care. There are also more specialist forms of care such as specialist dementia care, palliative care and recovery care. The type of support required depends on the individual's needs. Residential care homes provide personal care, such as washing, dressing and eating and in some of these homes, a few of the workers will have received specialist training in dementia support. Nursing homes provide personal care, as described above, but they also have a qualified nurse on duty 24 hours a day.9

^{6.} https://www.alzheimers.org.uk/info/20032/legal_and_financial/35/assessment_for_care_and_support_in_wales/5 [accessed 4 September 2018]

^{7.} Alzheimer's Society (2007), Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes, London: Alzheimer's Society. [accessed 4 September 2018]

^{8.} Alzheimer's Society (2007). Dementia UK. London: Alzheimer's Society.

^{9.} https://www.alzheimers.org.uk/info/20046/help_with_dementia_care/384/finding_a_care_home/2 [accessed 6 September 2018]

2. Dementia and language

- 2.1 The nature of dementia means that it can impair people's linguistic ability as it affects those parts of the brain which control language. It has long been understood that the condition leads to a general language decline amongst people with dementia and monoglot people, but much research has been published recently on the more specific effects on bilingual people.
- 2.2 There is a substantial body of international research and evidence which demonstrates the harmful effects of dementia on people's linguistic ability including, in some cases, a complete decline in the ability of bilingual people to speak one of those languages. There is also significant evidence in Wales, particularly through qualitative research, of the importance of the language of provision in delivering support to people with dementia.
- 2.3 When discussing the importance of the language of provision in delivering support to people with dementia as part of this project, Dr Catrin Hedd Jones, a Lecturer and Researcher in Dementia in the Dementia Services Development Centre Wales at Bangor University, said:
 - We must remember that receiving a service in the language that feels natural to people living with dementia is not a matter of choice but a clinical need, especially as the ability to communicate in their second language becomes more challenging for some.

If you question someone in the language with which they are most comfortable, you will glean more information about their situation. Some will be able to describe their feelings and emotions much more naturally if they're given the opportunity to do so in their first language, especially if they don't have the ability to express themselves as well in their second language. Help must be in place to support them in Welsh if that is most appropriate.

Dr Catrin Hedd Jones (Translation)

- 2.4 The importance of ensuring that people with dementia receive services in Welsh was highlighted in the report Welsh Speakers' Experiences of Health and Social Care Services prepared by IAITH (for the Welsh Government's Department for Health, Social Services and Children, and Care Council Wales) in 2012¹⁰. In producing the report, evidence was received from 51 respondents including four who had received a dementia diagnosis. For a number of respondents, using their language of choice was powerful in terms of creating affinity and forming closer professional relationships.
- 2.5 This supports the findings of the Welsh Language Commissioner's inquiry My Language, My Health. Although the work focuses on Welsh medium primary care, some elements are particularly relevant to people with dementia. The evidence received by the Commissioner from stakeholders and members of the public emphasised that the primary care sector must recognise that, for a number of patients, receiving a service in Welsh is a matter of need and not a matter of choice. The report explains that Welsh language services are needed by some patients who would otherwise face a real risk to their safety and welfare. To many, using English to discuss their inner, emotional life is difficult as there is no connection between the words in English and the experiences and emotions being discussed. Dr Catrin Hedd Jones underlined this when discussing the impact of not being able to receive a service in the most appropriate language:
 - Lack of effective communication can be dangerous when the needs of a Welsh speaker are misunderstood. On a wider level, the care and support delivered to people depends on developing a relationship and language is obviously a crucial element of that.'

Dr Catrin Hedd Jones (Translation)

3. The policy context

Relevant policies

Taking Wales Forward – Programme for Government 2016-21¹¹ and Prosperity for All: the national strategy¹²

- 3.1 The Welsh Government's programme for government for 2016-21 outlines the Government's commitments to a healthy and active Wales. In the context of care and older people the Government states that it will do the following, which applies directly to dementia care provisions:
 - ensure our ground-breaking social services legislation is fully implemented and all the benefits are realised.
 - take further action to make Wales a dementia friendly country through developing and implementing a new national dementia plan.
- 3.2 Prosperity for All takes those key commitments made in Taking Wales Forward and places them in a long-term context, and sets out how they fit with the work of the wider Welsh public service to lay the foundations for achieving prosperity for all. 'Better Mental Health' is one of the five cross-cutting priorities for this current Welsh Government term and in relation to dementia the commitment is made to help people with dementia and their families and carers to access information, advice and support to maintain their independence by a joint health service/local authority 'team around the family approach.'

^{11.} Welsh Government, *Taking Wales Forward – Programme for Government 2016-21* https://llyw.cymru/docs/strategies/160920-taking-wales-forward-en.pdf [accessed 19 July 2018]

^{12.} Welsh Government, *Prosperity for All: the national strategy* https://gov.wales/docs/strategies/170919-prosperity-for-all-en.pdf [accessed 19 July 2018]

A Healthier Wales¹³ and the Dementia Action Plan for Wales 2018-22¹⁴

- 3.3 In February 2018, the Welsh Government published the *Dementia Action Plan for Wales 2018-2022* which highlights its commitment to promoting the rights, dignity and autonomy of people living with dementia. The plan focuses on statements of rights for people living with dementia and their carers developed by people affected by dementia. These include an important statement in the context of care through the medium of Welsh and, indeed, in the context of the findings of this report in its entirety:
 - We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live. ■¹⁶

^{13.} Welsh Government, A Healthier Wales https://gov.wales/docs/dhss/publications/180608healthier-wales-mainen.pdf [accessed 17 August 2018]

^{14.} Welsh Government, *Dementia Action Plan for Wales 2018-22* https://gov.wales/docs/dhss/publications/180214dementiaen.pdf [accessed 19 July 2018]

^{15.} https://www.dementiaaction.org.uk/ [accessed 30 August 2018]

^{16.} Ibid., p. 4.

- 3.4 The action plan recognises the importance of delivering services in individuals' first language stating 'our service and community response needs to be equitable...and it needs to meet diverse needs...people who may be able to understand only their first language as their condition progresses'. The action plan is structured around outcomes which follow a pathway approach to dementia care. The Welsh language is crucial to all of the outcomes which form part of the dementia care pathway. 18 The action plan explains the importance of actively offering services through the medium of the Welsh language. It is also stated that the active offer commitment will be strengthened when the Welsh Language Standards for the health sector are introduced. The plan also emphasises that receiving care and support in Welsh is a clinical need for Welsh speakers with dementia and that as their condition progresses, people with dementia may understand or be able to communicate in their first language only. It makes the following specific commitment to dementia care in Welsh:
 - We will...work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary.

^{18.} Ibid., p. 31.

More than just words: Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019¹⁹

- 3.5 This strategic framework builds on the previous strategic framework for Welsh language services in health, social services and social care published in 2012. The framework sets out actions relating to seven objectives and assigns lead responsibility for completing them and by when. The seven objectives relate to the following matters:
 - National and local leadership, and national policy
 - Mapping, auditing, data collection and research
 - Service planning, commissioning, contracting and workforce planning
 - Promotion and engagement
 - Professional education
 - Welsh in the workplace
 - Regulation and inspection
- 3.6 More than just words 2016-19 specifically states that the Welsh language should be viewed as a fundamental element of dementia services.²⁰ It is stated that it is important to recognise the concept of language need as part of people's quality of care and as a clinical necessity. In addition, it is stated that health and social care and support services should be available in Welsh in order to maintain professional standards and meet the language needs of people as well as comply with legal and statutory requirements. Reference is also made to the European Charter for Regional or Minority Languages which establishes the principal that 'the right to use a regional or minority language in private and public life is an inalienable right'. Reference is then made to article 13 of the Charter relating to Economic and Social Life which is binding upon the UK Government and, therefore, the Welsh Government to ensure that social care facilities such as hospitals, retirement homes and hostels offer the possibility of receiving and treating in their own language persons using a regional or minority language which are in need of care on grounds of ill-health, old age or for other reasons.²¹

Welsh Government, More than just words: Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019 https://gov.wales/docs/dhss/ publications/160317morethanjustwordsen.pdf [accessed 19 July 2018]

^{20.} Ibid, p. 10.

^{21.} Ibid. p.13.

Cymraeg 2050 Strategy²²

3.7 The Cymraeg 2050 Strategy outlines the Welsh Government's intention to reach a million Welsh speakers by 2050, and for the percentage of the population that speak Welsh on a daily basis, and can speak more than just a few words of Welsh, to increase from 10 per cent (in 2013-15) to 20 per cent. One objective is to increase the use of the Welsh language in the workplace across all sectors. It is noted that increasing the use of Welsh in health and social care sector workplaces is extremely important in this regard. The relevance of the active offer principle is also highlighted when considering services in the health and social care sector in particular.

Relevant legislation

Social Services and Well-being (Wales) Act 2014²³

3.8 The Social Services and Well-being (Wales) Act 2014 contains specific requirements relating to the Welsh language including the language of assessment, considering the Welsh language when commissioning and delivering care and in individual care plans prepared in accordance with the Act. Section 14(1) states that local authorities and each local health board must jointly assess the range and level of services required to meet the care and support needs of people in the local authority area, as well as the range and level of preventative services required. They must also jointly assess the actions required to provide the range and level of services identified through the medium of Welsh. The Act and Regulations and the Part 2 Code of Practice include details on preparing care and support plans and specifically the rights and responsibilities of people who need care and support to achieve their personal outcomes. The Code states that when people use social services and their partners to implement their care and support plan, people can expect to achieve personal outcomes which reflect the national well-being outcome statement 'I get care and support through the Welsh language if I need it'.24

^{22.} Welsh Government, *Cymraeg 2050 Strategy* https://gov.wales/docs/dcells/publications/170711-welsh-language-strategy-eng.pdf [accessed 19 July 2018]

^{23.} Social Services and Well-being (Wales) Act 2014https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf [accessed 18 July 2018]

^{24.} Welsh Government, Social Services and Well-being (Wales) Act 2014 Part 2 Code of Practice (General Functions) https://gov.wales/docs/dhss/publications/151218part2en.pdf [accessed 18 July 2018]

Regulation and Inspection of Social Care (Wales) Act 2016 25

3.9 The aim of the Regulation and Inspection of Social Care (Wales) Act 2016 is to put quality and service improvement at the heart of regulation. It ensures that services deliver high quality care and support in accordance with the objectives of the Social Services and Well-being (Wales) Act 2014. Part 7, section 24 of the Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017, which arise from this Act, places requirements on service providers in relation to the standard of care and support that they deliver. The aim of Part 7 is to ensure that individuals receive care and support that enable them to achieve the best possible outcomes. The service will be planned in consultation with the individual and will consider their personal wishes, aspirations and outcomes and any risks and specialist needs which inform the care and support delivered. In terms of the Welsh language, it is stated in regulation 23 that 'the service provider must take reasonable steps to meet the language needs of individuals and the service provider must ensure that individuals are provided with access to such aids and equipment as may be necessary to facilitate the individual's communication with others.' The Statutory Guidance²⁶ resulting from these regulations outlines methods that could be adopted by service providers to help people with language and communication needs:

^{25.} Regulation and Inspection of Social Care (Wales) Act 2016, https://gov.wales/docs/dhss/publications/151218part2en.pdf [accessed 18 July 2018]

Welsh Government, Statutory guidance for service providers and responsible individuals on meeting service Standard regulations, p.36. https://beta.llyw.cymru/sites/default/files/consultations/2018-02/170502statutoryguidanceen.pdf [accessed 9 October 2018]

3.10 Care Inspectorate Wales inspects and drives improvement in regulated services and local authority social services. Care Inspectorate Wales' code of practice for inspection outlines the Inspectorate's intentions in fulfilling its duties in accordance with the Regulation and Inspection of Social Care (Wales) Act 2016. It is stated that the focus of its inspections is the quality and safety of services and the outcomes for people using these services.

Well-being of Future Generations (Wales) Act 2015²⁷

- 3.11 The Well-being of Future Generations Act requires public bodies in Wales, including Government Ministers, Local Authorities and Local Health Boards, to think about the long-term impact of their decisions; to work better with people; communities and each other; and to prevent persistent problems such as poverty, health inequality and climate change. The seven well-being goals to which these bodies are expected to contribute include the following:
 - A more equal Wales
 - A healthier Wales
 - A Wales of vibrant culture and thriving Welsh language

Welsh Language (Wales) Measure 2011²⁸ and the Welsh Language Standards

- The Welsh Language (Wales) Measure 2011 gives the Welsh language official status in Wales. The Measure also sets a legal framework which places a duty on some organisations to comply with standards. The standards explain how organisations are expected to use the Welsh language in different situations. The duties resulting from the standards mean that organisations must not treat the Welsh language less favourably than the English language, and that they should promote and facilitate the use of the Welsh language making it easier for people to use the Welsh language in their everyday lives. The purpose of the standards is to set out clearly for organisations their duties in relation to the Welsh language and to set out clearly for the public which services they can expect to receive in Welsh. Their aim is to ensure greater consistency in terms of the Welsh language services on offer and improve their quality. There are standards in the following areas:
 - service delivery
 - policy making
 - operational
 - promotion
 - record keeping
- 3.13 The Welsh Government and local authorities have been under a duty to comply with the Welsh language standards since 2016. It is anticipated that health boards and other health bodies will be under a duty to do so from 2019. It should be noted that the duties on health bodies will not extend to primary care provision, but that the Welsh Government will agree non-statutory duties for primary care bodies instead.

3.14 This section demonstrates that legislation and policies already in place create favourable conditions for delivering care through the medium of Welsh to people living with dementia. The Social Services and Well-being (Wales) Act 2014 means that the Welsh language is a consideration when preparing care and support plans and the Regulation and Inspection of Social Care (Wales) Act 2016 requires service providers to consult with individuals when planning their services and to take reasonable steps to meet individuals' language needs. More than just words 2016-19 and the Dementia Action Plan for Wales 2018-2022 also recognise that receiving care and support in Welsh is a clinical need for Welsh speakers with dementia. Both policy documents also highlight the importance of the active offer. There are clearly-defined actions in More than just words 2016-19 that would, if fully implemented, greatly complement and support the legislative requirements.

Part 2 The research and its findings

Overview of this section

- Dementia affects bilingual people in a different way to monoglot people and their care should reflect this.
- Providing care and services through the medium of Welsh is a basic clinical need for many Welsh speakers and people have a right to receive such care.
- Although there is good practice at a local level and the awareness of the Welsh language and the active offer at a strategic level has improved, the research suggests that there are many gaps in the care and very few examples where the needs of Welsh-speaking service users are being fully met.
- The research highlights inconsistency in the range of tools, diagnostic tests and assessment resources available for use in Welsh. The language of the provision offered can depend on the linguistic ability of the practitioners offering the provision.
- Although national policies emphasise that receiving care in Welsh is a matter of clinical need and not a matter of choice, this awareness and understanding has not filtered down into practice.

Service planning

- The research demonstrates that failure to collect and use sufficient data on the language skills of staff and service users and share this data between agencies is a barrier to service planning.
- There are doubts as to the extent to which the active offer has developed from being a policy concept to a reality which reflects a genuine understanding of the practical meaning of the concept.
- All professions involved in an individual's care plan need to take ownership of efforts to improve care and services for Welsh speakers.
- Positive examples were seen of requirements in relation to the Welsh language being included when commissioning services and monitoring them.
- There was very little evidence of multi-agency collaboration on a wide scale to ensure that people receive the Welsh language service they need. However, examples of good practice were seen, such as joint working with local groups and the third sector to fill gaps in staff skills and deliver a Welsh language experience.

Education, training and recruitment

- Recruiting people to work in the field is a problem in general and recruiting Welsh speakers is an additional challenge.
- The lack of training and awareness of the effects of dementia on Welsh speakers is also a challenge.
- The need for more language awareness training, to improve Welsh language skills as well as training through the medium of Welsh more generally, including online courses, was highlighted.
- The lack of confidence amongst staff in their Welsh language skills is a significant challenge.

1. Introduction to the research

- 1.1 This section demonstrates the main difficulties affecting the dementia care received by Welsh speakers. To do this, we have drawn together the findings of qualitative research that we commissioned and research that has been undertaken by others in the field. As part of the qualitative research that was commissioned visits were undertaken to eight locations across Wales where dementia care is provided. These included a wide variety of areas and settings, including public, private and third sector settings; day care centres, residential and nursing homes; and traditional Welsh-speaking areas and areas where the language is traditionally less spoken, as well as rural and urban areas. During these visits interviews were conducted with 14 practitioners and 18 individuals who lived with dementia and were at different stages of the condition. Five further interviews were conducted with senior officers from local authorities and health boards including those who have lead responsibility for dementia services in their areas and those who have lead responsibility for Welsh language services. In addition, two interviews were conducted with academics from the fields of dementia and health and social care. A round-table event was convened of people from different organisations with expertise in the field. The report also includes a summary of the answers received in response to freedom of information requests made by Alzheimer's Society Cymru in 2017. The aim of the information requests was to establish a baseline for the current Welsh language provision and the policy commitments which have been made to Welsh speakers with dementia.
- 1.2 As the research that was commissioned is based on consultation with a limited number of stakeholders an effort was made to make this sample as representative as possible. It should be emphasised that the report does not include a quantitative analysis of all the dementia services delivered across Wales. However, the research that we commissioned does include the opinions, experiences and testimony of people living with dementia and practitioners in the field. Together with research conducted by others it provides a representative picture of dementia care available to Welsh speakers.

The research

- visits were undertaken to eight locations across Wales where dementia care is provided.
- o interviews were conducted with 14 practitioners and 18 individuals who lived with dementia and were at different stages of the condition.
- five interviews were conducted with senior officers from local authorities and health boards
- two interviews were conducted with academics from the fields of dementia and health and social care
- a round-table event was convened of people from different organisations with expertise in the field
- a public event was held in the National Eisteddfod in Cardiff in 2018.

2. Dementia assessments

2.1 Evidence shows that the language of provision is extremely important when assessing and diagnosing dementia. Failure to deliver services in the most appropriate language can lead to delay in diagnosing dementia. It was also stated in our interviews with practitioners and experts in the field that the language of provision is essential when conducting diagnostic tests that are part of diagnosing dementia and it can impact people's performance in them. This is supported by international evidence and research studies undertaken in Wales. For example, according to research published in the Journal of Neuropsychology, 29 Welsh speakers receive a dementia diagnosis three years later on average than those who only speak English, and their cognitive condition will be a great deal worse by the time they receive that diagnosis. Dr Catrin Hedd Jones says that this may be due to a lack of bilingual services as well as cultural factors within Welshspeaking communities.³⁰ This is echoed in a research briefing³¹ prepared by Dr Catrin Hedd Jones for the National Assembly for Wales' research service. The briefing highlights the response to the research of a focus group with a team of community psychiatric nurses specialising in dementia. The research briefing states that three main themes arise from the focus group's discussions the influence of culture, mental health stigma and the importance of cultural sensitivity.

^{29.} Linda Clare, et al,' Bilingualism, executive control, and age at diagnosis among people with early-stage Alzheimer's disease in Wales', Journal of Neuropsychology, September 2016. https://onlinelibrary.wiley.com/doi/full/10.1111/jnp.12061 [accessed 16 August 2018)

^{30.} Golwg 360, 'Canfod dementia yn hwyrach mewn Cymry Cymraeg', 19 May 2017. https://golwg360. cymru/newyddion/cymru/264166-canfod-dementia-yn-hwyrach-mewn-cymry-cymraeg (Welsh only) [accessed 17 August 2018]

Catrin Hedd Jones, Research Briefing Access to dementia services for bilingual (Welsh and English) residents, National Assembly for Wales, 2018. http://www.assembly.wales/research%20documents/18-017/18-017-web-english.pdf [accessed 20 August 2018]

- 2.2 As part of her work with LLAIS (Language Awareness Infrastructure Support),³² Gwerfyl Roberts from Bangor University who currently works as an Independent Adviser translated and linguistically validated Welsh language dementia cognitive assessments.³³ Following this experience, she said that an individual's chances of obtaining a high score in the assessment depended on their proficiency in the languages being used. This supports international evidence which demonstrates that language is one of the main factors that affect cognitive screening tools:³⁴
 - Previous studies have demonstrated that while age and education are the most important determinants of normal variation in performance on cognitive testing, ethnicity and language may also affect selected items of standard cognitive screening instruments. This may be particularly important when assessing bilingual patients who may vary in comprehension and performance on cognitive tests depending on the language used to administer the tests.
- 2.3 Alzheimer's Society Cymru also drew attention to these challenges during the development of the Dementia Action Plan for Wales 2018-22. Specifically, it emphasised the difficulties experienced by Welsh speakers in the process of obtaining a dementia diagnosis. Reference was made to Public Health Wales' audit of memory clinics in 2014³⁵ which stated that 'Welsh language assessment was available in all clinics, but usually by involving a Welsh-speaking colleague from another service'. The report did not identify this as a weakness in the service however. Alzheimer's Society Cymru hoped to see further details in the Action Plan on how the Welsh Government would ensure that Welsh speakers can access dementia services. It was recommended that only qualified assessors should be involved in diagnosing dementia and where there are no Welsh-speaking assessors, clinics should take action to train Welsh speakers to diagnose dementia.

^{32.} http://nworth-ctu.bangor.ac.uk/llais/staff.php.en

Bangor University, LLAIS (2014) Cognitive Assessment Toolkit http://nworth-ctu.bangor.ac.uk/ documents/25714CognitiveAssessmentToolkitCYMRAEG.pdf.

^{34.} Aaron McMurtray, MD, Erin Saito, MSc, and Beau Nakamoto, MD. 'Language Preference and Development of Dementia Among Bilingual Individuals', Hawaii Med J. 2009.

^{35.} Public Health Wales, Wales National Audit Memory Clinic and Memory Assessment Services, 2014. https://www.rcpsych.ac.uk/pdf/Wales%20National%20Audit%20-%20Memory%20Clinics%20Aug%202014.pdf [accessed 17 August 2018]

- 2.4 We know that a number of dementia diagnostic tests are available in Welsh (e.g. MOCA, ACE III) and information about these is available on the Mi-Cym website.³⁶ However, in general, the evidence highlights inconsistencies in the range of tools, diagnostic tests and resources used with Welsh speakers. The freedom of information requests from Alzheimer's Society Cymru revealed some inconsistency in the dementia diagnostic tests available for Welsh speakers living with dementia. One health board stated that they were aware of one Welsh language dementia diagnostic test which had been validated and that they ensure that it is available to doctors. However, the responses to the request for information about whether tests were used in Welsh were inconsistent. In the round-table discussion, it was noted that not all of the professionals in the field recognise and take ownership of the Welsh language tests that are available due to doubts about their quality and validity. It was noted, however, that the same could be said for English language tests used with Welsh speakers too because they have not been moderated to consider Welsh speakers or bilingual people.
- 2.5 Research from 2003 conducted by Morgan and Crowder³⁷ studied the response of bilingual people with Welsh as a first language to the MMSE (Mini Mental State Examination) cognitive test.³⁸ It showed that the same people achieved a different score when completing the test in Welsh and in English. This, according to the researchers, was a cause for concern as the result of the test affects the care subsequently received by these people. As noted in the research:
 - It is felt that misleading results are being achieved for Welsh speaking patients. In the context that decisions about the allocation of health and social care services are increasingly made on the basis of people's scores on a screening instrument this may have potentially significant consequences, both for those concerned whose ability to live independently may be questioned and also for the health and social care services where resources may be inappropriately targeted.

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^{36.} http://www.micym.org/llais/measure/index http://www.micym.org/llais/static/index.html [accessed 12 September 2018]

^{37.} Tracey Morgan, Ruth Crowder. 'Mini Mental State Examinations in English: are they suitable for people with dementia who are Welsh speaking?', 2003. http://journals.sagepub.com/doi/abs/10.1177/14713 01203002002009

^{38.} This test has now been superseded by more recent tests.

^{39.} Ibid. p. 271.

- 2.6 The research undertaken in care settings showed once again that the language of tests depended on the language of those conducting them. Evidence suggested that some Welsh speakers undertake cognitive tests in English relying on others to translate them into Welsh. These were sometimes members of staff who were not trained to conduct the tests nor were they qualified translators. We also heard of carers or family members having to translate. As one manager of a care location said:
 - I sat in on two tests some weeks ago and the psychiatrists didn't speak Welsh. I was there to translate but I found it difficult to understand them and I felt quite uncomfortable. It wasn't fair on the individual because this is important, the tests are hard enough as it is but not being able to do them in your first language is even harder. I have never seen a psychiatrist conducting the test in Welsh.

Care location manager (Translation)

- 2.7 The research by Morgan and Crowder also stated that it is crucial that assessments are undertaken by bilingual workers in order to ensure that individuals receive the best care, as follows:
 - Each public body must have its own procedures to accommodate Welsh speakers. It is essential that clients are treated individually using bilingual staff as it is believed this is the only way to ensure that Welsh speaking clients with dementia receive the client-centred and holisitic assessment they require. 40

- 2.8 It also became clear that there was uncertainty regarding which cognitive tests are available, the language of provision and the support delivered to Welsh speakers taking these tests.
 - We must understand whether the tests which have been translated are being offered by memory clinics. Is it dependent on having bilingual staff? If receiving a Welsh language service led to delay, there's a risk that Welsh speakers would make do with the English language test and this could mean that they wouldn't perform to best of their ability. Staff need to be there to ensure that bilingual individuals don't feel that they're causing trouble if they wish to receive the service and, importantly, their tests through the medium of Welsh.

Dr. Catrin Hedd Jones (Translation)

2.9 In the IAITH study of Welsh Speakers' Experiences of Health and Social Care Services one respondent referred to the difference they saw when they took a relative to a memory clinic where the assessment was not available through the medium of Welsh and then took them to see a Welsh-speaking psychologist. In the first case, the relative was described as being agitated and she had to be forced to stay there. In the second case, the respondent said that the psychologist explained that she uses every day Welsh ... The diagnosis is the same but we feel different.' The report explains that 'the essential difference, is that having a shared language and an associated understanding of culture has helped create a clinical relationship'.⁴¹

3. The demand for Welsh language services

I'm happier speaking Welsh to people but there are very few Welsh language services here. No one asks us [about our language choice for services]. ■

Person with dementia (Translation)

- 3.1 Alzheimer's Society Cymru's freedom of information request revealed a lack of data amongst health boards and local authorities alike about the number of Welsh speakers accessing dementia support services and their language choice. The case studies gave examples of organisations which deliver care and support to people with dementia and the availability of those services through the medium of Welsh. The research sample was insufficient to provide definitive findings about the nature of services but, put together, the case studies provided useful evidence to create a general picture of the linguistic nature of dementia services in Wales.
- 3.2 According to Alzheimer's Society, 42 1 in 14 individuals over 65 years old in the UK are living with dementia. Therefore, even in those areas with fewer Welsh-speaking inhabitants, there will be several cases of Welsh speakers with dementia. In counties with higher percentages of Welsh speakers, it is likely that several hundred or indeed thousands of Welsh speakers have dementia. Therefore, even though the demand for Welsh language services is currently much higher in the more Welsh-speaking areas in north, mid and south-west Wales, the research revealed several cases of demand for Welsh language services in areas with lower percentages of Welsh speakers, such as the south-east. The demand for Welsh language services, therefore, varied between settings and areas but there is a need for Welsh language services in all of the settings and areas covered by this study. The long term consequences of the recent increase in the number of Welsh speakers in those areas with traditionally fewer Welsh speakers must also be borne in mind. This population will of course age with time.
- 3.3 Most of the settings visited assessed service users' language needs before they arrived at the home/centre and/or asked their family to complete an information pack which included a section on the language of the individual with dementia. Three practitioners said that they receive this information from social services and all but one of the settings said that they have a systematic approach to identifying service users' language needs.

3.4 The research suggested, therefore, that these services assess the language needs of residents/service users on the whole. However, during one interview, it was said that there is a reliance on the family to disclose information about individuals' language needs. The round-table discussions revealed that information about individuals' language needs was not always shared effectively between various agencies. In addition, the freedom of information request to local authorities found a lack of clarity regarding the way in which information about the language needs of Welsh speakers with dementia was disseminated between services.

4. Delivering a Welsh language service and the active offer

There are hardly any Welsh language services available now. Hardly anyone can speak Welsh here but there are some Welsh language activities. I would be far happier if there were more Welsh language services. It isn't always easy expressing yourself in English. If I ask, I do sometimes get things in Welsh, but I don't normally ask. ■

Person with dementia (Translation)

- 4.1 One of the basic principles when considering the extent to which an adequate Welsh language service is being offered is whether an active offer is made or whether the patient is expected to ask for the service, or whether there are any barriers to receiving a Welsh language service. In the paper Welsh Speakers' Experiences of Health and Social Care Service⁴³, a number of service users and carers said that Welsh language services were delivered on the basis of demand rather than need. The paper concludes that the onus should be placed on the provider to ask the question rather than on the service user to identify the need, and that this is particularly pertinent for vulnerable service users.
- 4.2 My Language, My Health comes to a similar conclusion. The responses to the Inquiry demonstrated that a number of Welsh speakers make do with primary care service in English even though they would prefer to speak Welsh. It is noted that several factors contribute to a patient's reluctance to ask for a Welsh language service, including the perception that there is no language choice available in most cases and that it is only available in other areas by chance. The unequal balance of power between the service provider and the patient makes it very difficult for a patient to change the situation by asking for a Welsh language service.

4.3 This is supported by the research undertaken in care settings. Even though they had information about the language needs of people with dementia, they did not always actively offer a language choice. It was clear from some of the interviews conducted with people with dementia that they avoided asking for a Welsh language service. Some of the interviews with service providers demonstrated ignorance regarding the importance of the active offer, with some assuming that people are equally comfortable in Welsh and English if they do not ask for a Welsh language service. However, this varied between settings and others said that they actively offered a language choice. The general shortage of dementia services can also mean that people who need support are reluctant to demand a Welsh language service due to concerns that they will not receive any support at all. This in turn makes it difficult to demonstrate the need for Welsh language services.

I do [speak Welsh], but they don't understand.

Person with dementia (Translation)

Alzheimer's Society Cymru's freedom of information request demonstrated that the majority of local authorities confirmed that they have a high level policy commitment to delivering bilingual services to people with dementia, with several references to the active offer. As such, requirements in relation to the Welsh language were also included in a significant number of service commissioning specifications. However, the freedom of information requests revealed several cases where local authorities relied on translators to deliver services. In addition, in some health board areas, there was evidence of difficulty in delivering a full care pathway through the medium of Welsh to Welsh speakers with dementia, although efforts are being made in this direction.

- 4.4 Not all care settings had considered workforce planning in such a way as to deliver a Welsh language service across the service (e.g. general care, nursing etc.). There was also inconsistency in the way in which the settings visited planned their services purposefully to ensure that Welsh language services were available to those who required them. Two settings stated that they ensure that Welsh speaking carers are on duty on every shift. Another stated that they did not have enough Welsh-speaking staff to ensure that there were Welsh speakers on the rota at all times, but that they tried to pair Welsh-speaking staff and residents where possible. Staff caring for one of the Welsh-speaking residents in one home had learnt some simple phrases, but there were no fluent Welsh speakers available to be able to plan a more comprehensive Welsh language service.
- 4.5 In the areas where less Welsh was spoken, there were very few Welsh-speaking staff and therefore it was not possible to deliver full care and support through the medium of Welsh. As a result, some of these settings relied on other ways of delivering some kind of Welsh language service. One setting had established close links with local Welsh language organisations, including Mudiad Meithrin, in order to hold events and activities through the medium of Welsh for residents. One setting had translated many of its resources into Welsh and two homes offered televisions and radios to enable residents to hear the Welsh language through those media. Many of the practitioners stated that the focus placed on the Welsh language has increased significantly over recent years and that it is becoming far more of a live issue. This mixed picture was supported by comments from people with dementia and a number of residents said that they do not believe that there are enough Welsh language services available to them.

- 4.6 It became clear also that difficulties arise when people living with dementia come into contact with services outside the care settings. This highlights weaknesses in terms of collecting, recording and sharing information about people's language needs and ensuring that this information informs wider workforce and service planning. In general, it was seen that support providers give priority to delivering the service rather than waiting for Welsh speakers when moving from one service to another. A number of settings said that they ask for a Welsh speaking professional when a service user requires an external service, but that this depends on the service's ability to meet the request.
 - We do everything in Welsh. The only service which may be delivered in English is the medical side when doctors are treating them and so on. With locums, it's impossible to get the same GP every time and so some of the ones that visit don't speak Welsh... Perhaps the main challenge is a lack of Welsh-speaking psychiatrists.

Care location manager (Translation)

There is a general awareness at a policy level of the clinical need to offer care through the medium of Welsh to people with dementia and, indeed, policy commitments have been made in response to this need. However, it does not appear that this awareness and action to fulfil these policy commitments have filtered down to grass roots level so that professionals in the field understand that receiving care in Welsh is a matter of clinical need rather than choice.

I think that multi-agency support [is the main gap] where there aren't many Welsh-speaking professionals, in terms of the medical profession as well as local social groups.

Care location manager

5. The workforce

✓ Very few of the staff speak Welsh, most of them are English speakers... I've been to see the doctor but they're English too... I have to speak English with them. ■

Person with dementia (Translation)

- 5.1 It is essential to ensure that there is an adequate number of people in the health and social care workforce that can provide services through the medium of Welsh and that people are aware of the active offer and the care needs of Welsh speakers. It is essential therefore that there are steps in place to collect data about Welsh speakers and that the workforce is planned and trained on the basis of data. Despite this, from the research undertaken in care settings, it was seen that the ability of the workforce to deliver a service in Welsh, and the efforts made to ensure that people have sufficient ability and the means to develop that ability, vary widely from setting to setting and from area to area. In one setting, all of the staff spoke Welsh and in another two settings, more than 50% of the staff were Welsh speakers. In two settings, there was a big gap between the percentage of staff who could speak Welsh and the percentage of residents who could speak Welsh (8% to 42% and 17% to 50%). In another setting, even though there were two residents who required Welsh language services, there were not enough Welsh speakers to deliver a regular Welsh language service. An inconsistent approach to recruiting Welsh speakers was seen across Wales, with some job descriptions stating that the Welsh language is essential and others stating that it is desirable. The ability to speak Welsh was not considered part of the quality of care that an individual could offer to residents.
 - Our job descriptions don't currently state that the Welsh language is essential because that would make it difficult to recruit anyone, but it would be nice to have more Welsh-speaking members of staff. It would also be good to have more Welsh-speaking professionals in the field, including doctors, nurses and external agencies.

Care location manager

- 5.2 In general, evidence from these case studies suggests that few care locations, assess workers' language skills and record that information in a formal and systematic way. Several said that they get an insight into the Welsh language skills of staff during the interview process and a few relied on the fact that they know the staff or come to know them. One manager said that they could only estimate the number and that they would guess that some members of staff may have Welsh language skills of which the manager is unaware. Examples were also seen of a lack of confidence amongst people with Welsh language skills to use the language.
- 5.3 From the evidence of members of the round-table and comments from two events held by the Welsh Language Commissioner, Alzheimer's Society Cymru and Theatr Genedlaethol Cymru, and the other by Social Care Wales in the National Eisteddfod in Cardiff in 2018 to discuss dementia care, it was emphasised that one of the main challenges in the field was a lack of confidence within the workforce in their language skills. It was noted that a number of people felt that they should not use Welsh at all if they could not deliver a full Welsh language service. Several emphasised the need to encourage workers delivering services to people with dementia to use the Welsh skills that they have, whatever their level. It was also noted that cultural awareness is crucial in order to be able to discuss with people with dementia in Welsh.
- 5.4 The importance of providing Welsh lessons for health board staff was also discussed. Reference was made to requirement in Sweden that clinical health professionals are required to possess sufficient language skills in order to obtain a licence to practise.44 The individual in question was released from work on full pay in order to learn the language. Currently, authorities and organisations managed by local authorities have a specific duty to assess and develop the Welsh language skills of their staff due to the Welsh language standards. In 2019, the same requirements will apply to health boards. These standards will require health bodies to assess the language skills of their workforce and provide training for staff to learn Welsh and develop their Welsh language skills, as well as raise awareness of the language and improve understanding of the way in which Welsh can be used in the workplace.

- 5.5 The research found significant evidence that most settings try to improve the Welsh language skills of their workforce. Many care homes and day centres said that they encourage staff to attend Welsh courses and that many of them do so. Only two of the eight said that they do not have any specific structures in place to improve the workforce's ability to deliver Welsh language services. The need for more language awareness training, Welsh language improvement training as well as training through the medium of Welsh more generally, including online courses, was highlighted.
- 5.6 In general, there is lack awareness of the needs of patients living with dementia. Successful initiatives such as This is me⁴⁵ and the Butterfly Scheme⁴⁶ have helped to raise awareness amongst professionals in care settings. Similar initiatives should be developed to ensure that health professionals are aware that patients need care and support in Welsh, especially people with dementia. To achieve this, strong leadership in relation to the Welsh language and an understanding of the active offer is required from health professions involved in dementia care as well as senior officers within local authorities and health boards. However, the freedom of information request to health boards revealed a difference of opinion in several areas between clinical leaders responsible for dementia care and corporate leaders responsible for the Welsh language. It was noted that clinical leaders did not always recognise the clinical importance of delivering Welsh language services to people with dementia. It was seen that further collaboration is needed to overcome this. In this regard, the round-table discussions revealed the need for all professions involved in the care package of people with dementia to recognise the importance of the Welsh language as a clinical need when delivering care. It was noted that all professions need to take ownership of efforts to change and improve the care delivered in order to create change and improvement.

^{45.} https://www.alzheimers.org.uk/about-us/wales [accessed 12 September 2018] https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me_bilingual_welsh.pdf

^{46.} https://www.pembrokeshire.gov.uk/hospital-care-admission/butterfly-scheme [accessed 6 September 2018]

6. Impact on service users

As their dementia develops, we've noticed that some of the residents feel more comfortable discussing their personal needs in Welsh. This is something which happens often.

Care location manager (Translation)

- 6.1 Unfortunately, the research revealed examples where a lack of Welsh language services has had a harmful effect on people. In one case, an individual had started to lose her grasp of English and spoke Welsh to staff even though they did not understand her. This caused great frustration to the individual:
 - I think that she gets very frustrated when we don't understand what she's trying to tell us, especially if she's in pain or upset about something. As staff, we've discussed not asking her to repeat everything in English because that makes her feel very frustrated. The staff who have been here since she moved in understand her needs well, but maybe some of the new staff can make her feel frustrated... When she came to us initially, she had lived in the area for a long time and she spoke English with us easily. But, lately and after her dementia progressed, she has started to speak a lot more Welsh with us.

Care location manager

- 6.2 In another case, a resident did not speak at all and staff were unaware that he was a Welsh speaker. Therefore, for a period, he did not talk to anyone until staff found out, by chance, that he was a Welsh speaker. It is difficult to imagine the experience of this individual and the pain of not being able to communicate with those around him even though he had a language of communication.
 - One of our residents, who is no longer with us, refused to talk to anyone so we thought he couldn't talk. Subsequently, one of the managers here, whose first language is Welsh, happened to say a few words of Welsh to the resident and he started talking to him straight away not in broken Welsh but fluent Welsh. He had dementia and he would only speak in Welsh. It was only by chance that we found out. Learning about this completely changed the way I think about the service and the opportunity to speak Welsh had a big impact on him.

Care location manager

- 6.3 In the IAITH study of Welsh Speakers' Experiences of Health and Social Care Services several respondents refer to the way in which language use can either agitate or placate an individual with dementia. One respondent, discussing the experience of his father who had been admitted to hospital and who had lost grasp of English completely, said that 'there were two people who spoke Welsh on the ward and when one of these happened to be on duty, he'd be quieter... It makes the condition a lot worse if you can't communicate in your first language. If there weren't any Welsh speakers on the shift, he used to be wild. He'd stare. His arms used to flay around... It's the last thing you learn which is the first to go with dementia.' 47
- 6.4 These examples and other sections of this report underline the fact that offering care in Welsh is a clinical need for Welsh speakers with dementia and that they have a right to receive such care. If care is not available to individuals in Welsh, it constitutes a weakness in the care delivered, which is harmful and impacts their care. More than just words states that 'ensuring the safety, dignity and respect of Welsh speakers is at the heart of providing health and social services in Welsh...it is also about improving the quality of care and meeting the language need of people and providing good public services that focus on the individual'.48 These examples do not focus on the needs of the individual nor do they ensure their dignity and respect. It can be interpreted, therefore, that these services which affect individuals' clinical care - be they public, private or voluntary - are not good services. At an all Wales level, therefore, it appears that dementia care for Welsh speakers is inadequate. This is unacceptable.

Part 3 Policy recommendations

1. Full implementation of legislation and policies

1.1 Part 1 of this report demonstrates that legislation and policies already in place create favourable conditions for delivering care through the medium of Welsh to people living with dementia. Taken together, legislation and policies in favour of the Welsh language in care are relatively powerful. However, the findings in Part 2 of this report reveal gaps in the implementation of these policies and legislation leading to gaps in the care currently delivered to individuals living with dementia. These gaps represent a failure in care. We therefore conclude that these policies and legislation need to be implemented, reviewed and inspected more effectively and action taken in response to the findings. We also conclude that there is a need to promote the understanding of the clinical need of people with dementia to receive services in Welsh and that this right needs to be upheld through service planning, collaboration between agencies, and recruitment, education and training processes for professionals involved in the care package of people with dementia.

Recommendation 1

We ask the Assembly's Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it'⁴⁹ is being met in relation to dementia care. Specifically, the consideration given to the Welsh language in the following areas should be examined:

- assessments
- commissioning and delivering care
- individual care plans
- how local authorities and local health boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

Recommendation 2

We recommend that Care Inspectorate Wales and the Healthcare Inspectorate Wales recognise that a lack of Welsh language care for those who require it constitutes poor care which may have a harmful effect on people. The ability of providers to offer care in Welsh to people with dementia should constitute good practice and be a measure of the quality and safety of services. This should form part of their inspection work.

2. Develop a Welsh language dementia care pathway

2.1 The Welsh language, understanding of the impact of dementia on Welsh speakers and a recognition of the rights of Welsh speakers with dementia should be central to the vision of the Dementia Action Plan for Wales. Despite the commitments in current legislation, the research demonstrated that the Welsh language is often an 'additional' consideration in terms of dementia care. The Action Plan states that people living with dementia and their families and carers have said that a support system needs to be developed which is 'flexible – with services able to respond to an individual's needs rather than expect people to adapt to what exists already... and able to respond to the language and cultural needs of their population. 150 lt states the Welsh Government's commitment to 'develop a consistent clearly understood diagnosis, care and support pathway which incorporates standards of care and outcome measures'. The Plan also states the intention to 'develop multidisciplinary 'teams around the individual' which provide person-centred and coordinated care, support and treatment as needed.'51

Recommendation 3

We ask the Welsh Government, in implementing the *Dementia Action Plan for Wales*, to consider the extent to which the relevant targets set for health and social care services in *More than just words* have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision. If they have not been met, steps should be taken to rectify this in order to facilitate implementation of the Action Plan and other recommendations made in this report.

Recommendation 4

We ask local authorities, health boards and the Welsh Government to work together to develop a Welsh language care pathway. This is a golden opportunity to ensure that the Welsh language is central to individuals' care pathways and that staff working with them and their families can respond to their language needs.

Recommendation 5

We ask the Welsh Government to produce a specific action plan to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams which form part of the Action Plan, in order to ensure that the care commitments made in the Social Services and Well-being (Wales) Act 2014 are fulfilled.

3. Collaborate to share resources and information

- 3.1 The *Dementia Action Plan for Wales* states that 'diagnostic tools must be available in a variety of languages, which are culturally appropriate, and in various formats to ensure that health boards can meet the needs of their population.'⁵² Specifically, in the context of the Welsh language, the commitment is made. We will work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary.'⁵³
- 3.2 This commitment is to be welcomed, of course, but it needs to go further and develop and maintain a national online platform providing quality Welsh language resources for dementia workers and carers. We know that a number of resources are available on the Mi-CYM⁵⁴ website and that some health boards refer to these resources, but there is inconsistency across Wales. Further work needs to be undertaken to ensure that standardised translations are available and that further assessments in the field of dementia care are validated. This is in addition to developing guidelines and training to conduct tests and assessments with Welsh speakers and collecting anonymized data to set the norms for Welsh speakers undertaking test. The Welsh Government needs to raise awareness of these resources and ensure that they are recognised by the different professions working with people with dementia, including psychiatrists and clinical psychologists. It must also be ensured that these tests are administered by people who can do so through the medium of Welsh.

Recommendation 6

As part of the commitment above to undertake further work on dementia assessment tools we ask the Welsh Government to work with local authorities and health boards in Wales to develop a national platform to share Welsh language tests as well as resources, expertise and information about dementia and the Welsh language. This will ensure that they are recognised by the different professions working with people with dementia and raise awareness of them amongst health and social care workers.

^{52.} Ibid., p. 16

^{53.} Ibid., p. 16.

^{54.} http://www.micym.org/llais/static/index.html

3.3 Participants in the round-table discussions also suggested that a national forum should be developed to enable dementia workers delivering care in Welsh to share information and support each other. Regional forums could contribute information to this national forum. It should be ensured that people living with dementia and their carers are prominent in these forums.

Recommendation 7

We ask the Welsh Government along with health boards and local authorities to develop national and local forums to share experiences of delivering care and volunteering in Welsh which would contribute experiences and information to the national platform mentioned above.

3.4 Even when language needs and choices are recorded by a specific service, difficulties were seen to arise when transferring this information between services. The Welsh Government should ensure that there are systems in place to record and transfer this information between agencies effectively. The Welsh Community Care Information System (WCCIS) and GP records are examples of such systems.⁵⁵

Recommendation 8

We ask the Welsh Government to put technology in place to ensure that information about patients' language choice and needs is recorded and that this information is transferred effectively between health and social care services.

3.5 Leadership is essential in this field and leaders in health and social care fields need to take professional responsibility for ensuring that awareness and understanding of the needs of people with dementia is disseminated and is fully considered when planning and providing services. The *Dementia Action Plan for Wales* refers to the Government's intention to create a new All Wales Dementia Allied Health Practitioner post. They will provide advice and support to health boards and local authorities to drive service improvement.

Recommendation 9

We ask the Welsh Government to ensure that the new Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia. This can include raising awareness of the importance of the active offer, in order to drive service improvement and raise awareness of the importance of the language of provision when delivering dementia care.

Recommendation 10

We ask the Welsh Government to ensure that the equivalent responsibility or post to the All Wales Dementia Allied Health Practitioner is created in the clinical field in order to provide clinical advice and leadership and support in relation to dementia and the Welsh language to health boards, local authorities, health professions and others, and to raise awareness of the importance of the language of provision and the active offer when delivering dementia care. This national leader could be responsible for developing the platform and national forums in recommendations 6 and 7 also.

4. Develop and raise the awareness of the workforce

4.1 The findings of the research demonstrate clearly that a lack of Welsh-speaking staff is the main barrier to offering Welsh services to people living with dementia. More than just words highlights that a lack of data on Welsh speakers within the workforce impedes not just workforce planning but also restricts the process of providing appropriate training and support to enable the workforce to develop their Welsh language skills. There are specific actions for NHS Wales Chief Executives and Directors of Social Services relating to collecting data and establishing language profiles of communities and the workforce⁵⁶ in order to plan Welsh language service provision and provide the active offer to individuals. Obtaining such data is crucial for workforce planning. In autumn 2018 Health Education and Improvement Wales will come into being and this body will have an important role in training and developing the Welsh health workforce.

Recommendation 11

We ask that the commitments made in *More than just words* relating to collecting data about the linguistic needs of the public and the language skills of the workforce be implemented fully and promptly in relation to delivering dementia services by local authorities and health boards. Based on this information Health Education and Improvement Wales, should cooperate and strategically plan with higher and further education establishments, the Coleg Cymraeg Cenedlaethol and health boards to commission places for Welsh speakers on relevant training courses and ensure that Welsh speakers are aware of the need for Welsh speaking health and social care workers and the opportunities open to them.

Recommendation 12

We recommend that Health Education and Improvement Wales should ensure that language awareness, an understanding of the impact of dementia on bilingual people; the fact that offering health and social care provision in Welsh is a clinical need for a number of Welsh speakers; the rights of Welsh speakers to receive services in Welsh, and the importance of the active offer are an integral part of the education and training of all health service professionals across Wales. This should be part of the initial training of health workers and part of their continuing professional development, and especially part of the training of leaders in these fields.

4.2 The Dementia Action Plan includes a commitment to 'reviewing and standardising the role of dementia support workers – increasing their numbers as required' and to develop 'teams around the individual'. Reviewing and standardising the role of dementia support workers and developing new teams offer an important opportunity to include Welsh language skills as a requirement for new posts in the field of dementia and to ensure that Welsh speakers enter the dementia care professions.

Recommendation 13

We recommend that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual as part of the Dementia Action Plan.

Recommendation 14

We recommend that the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care package of people with dementia and of leaders in the field. Based on this audit, plans should be made to raise awareness of these matters amongst these workers, e.g. by undertaking a specific campaign to raise awareness of dementia and the active offer.

4.3 Work is already underway to develop new Health and Social Care and Child Care qualifications for Wales and it is hoped that these new qualification will raise awareness of the importance of offering care in Welsh and the active offer as well as other cultural considerations. It should be ensured that it is possible for Welsh speakers to undertake these courses in full and that an adequate number of Welsh speakers do so. There is a joint project underway between the National Centre for Learning Welsh and Social Care Wales to develop the Welsh language skills of the current workforce. It must be ensured that these courses are available to all workers involved in the care package for people living with dementia.

Recommendation 15

As part of the Welsh Government's *Dementia Action Plan for Wales* and in light of the requirements that are and will be applicable to them in accordance with the Welsh language standards, health boards and local authorities should ensure that specialist Welsh learning provision is available for workers involved in the care package for people living with dementia, using the plans offered by the National Centre for Learning Welsh for example. Where possible, relevant health and social care workers from all professions should be released for extended periods to develop linguistic skills that will enable them to provide dementia care through the medium of Welsh.

4.4 As well as these recommendations made jointly by Alzheimer's Society Cymru and the Welsh Language Commissioner, we believe that full consideration should be given to implementing the recommendations made in the research briefing prepared by Dr Catrin Hedd Jones for the National Assembly for Wales' Research Service.⁵⁷ Many of these recommendations complement the recommendations made in this report.

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Appendix 1

Round-table members

Beti George, person affected by dementia and broadcaster
Sue Phelps, Alzheimer's Society Cymru
Meri Huws, Welsh Language Commissioner
Conor Martin, Betsi Cadwaladr Health Board
Catrin Hedd Jones, Bangor University
Gwerfyl Roberts, Independent Consultant
Rachel Rahman, Aberystwyth University
Emma Harris-Jones, Dementia Support Worker, Alzheimer's Society
Cymru
Eirlys Rowlands, person affected by dementia
Marc Roberts, Care Inspectorate Wales
Meilyr Emrys, Betsi Cadwaladr Health Board
Anke Cupok, Royal College of Psychiatrists
Julia Rose Kramer, Royal College of Psychiatrists
Sandie Grieve, Social Care Wales

Officers

Morgan Griffith-David, Alzheimer's Society Cymru Sophie Douglas, Alzheimer's Society Cymru Steffan Bryn, Welsh Language Commissioner Dyfan Sion, Welsh Language Commissioner Lowri Williams, Welsh Language Commissioner

Notes	





Comisiynydd y Gymraeg Welsh Language Commissioner

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