



# Research Briefing **Access to dementia services for bilingual (Welsh and English) residents**

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**National Assembly for Wales**  
Research Service

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## Research Briefing

# **Access to dementia services for bilingual (Welsh and English) residents**

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This paper is published as part of the Assembly's pilot Academic Fellowship Scheme, which enables academics to work at the Assembly on a specific project, for the mutual benefit of the academic and the Assembly.

The paper sets out recommendations on how to ensure that bilingual residents in Wales receive equal access to dementia services.





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# 1. Introduction

The Welsh Government's consultation draft of the dementia strategy for Wales referred to “anecdotal evidence that some communities such as Welsh language... communities may be less likely to talk about dementia” (p.17, Welsh Government [WG], 2017). The aim of this paper is to set out evidence and make recommendations about access by Welsh speakers to timely and appropriate support.

This paper developed from discussions within the Dementia Services Development Centre Wales (DSDC Wales), Bangor University academics in Healthcare, Bilingualism and Psychology, a team of Community Psychiatric Nurses (CPN) specialising in Dementia and the North Wales Ageing Well Network hosted by the Older People's Commissioner for Wales. The paper includes 10 recommendations, which aim to address issues around access to services in Welsh to promote equality in dementia support services. Further research is required to understand the geographical variation in utilisation of memory services and diagnosis, based on GP clusters.

The DSDC Wales was established as part of a UK network in 1999 to provide information, training and dementia care related research. The team of researchers, led by Professor Bob Woods and Dr Gill Windle, have international expertise in psychosocial care, resilience in old age, and host the North Wales Dementia Network, a cross sector group encouraging best practice in dementia care and dialogue with individuals affected by dementia. The DSDC team also lead Bangor University's contribution to the Centre for Ageing & Dementia Research, in collaboration with Swansea and Cardiff Universities as part of the Health & Care Research Wales research structure.

## 2. Current research

There is now some evidence that bilingual people with dementia access services between 4.3 and 7.3 years later than their monolingual peers (Alladi et al., 2013; Bialystok, Craik, & Freedman, 2007/ 2010; Bialystok, Craik, Binns, Osher & Freedman, 2014). At first glance, this delay in diagnosis could be seen as a positive result of a flexible brain maintaining abilities in older age. However, in recent research undertaken here in Wales, bilingual individuals were on average, three years older accessing the service, but also had more severe dementia symptoms (Clare et al., 2016). Although it is not possible to be certain from reading this research why their symptoms are more severe than the monolingual patients (that was not the purpose of the research), this outcome suggests that patients (i) were not detected early enough or (ii) did not attend a clinic early enough. This paper aims to identify the possible reasons for the severity of bilingual patients' symptoms when they come to the attention of services. The goal is to ensure that everyone has access to the support they need.

## 3. Consultation with the workforce and specialists in healthcare, language and dementia.

A focus group of Community Psychiatric Nurse practitioners working in a bilingual community was initially facilitated by Dr Catrin Hedd Jones (3/10/17) with the research published by Clare et al. (2016) forming the basis of the discussion. A summary of the issues raised at the meeting formed the basis for further discussions with academics and managers of services for older people in North Wales (12/10/17).

**Table 1 Membership of the consultation groups**

<b>Consultation group</b>	<b>Number</b>	<b>Ratio of bilingual speakers: English only</b>	<b>Posts</b>
<i>Mental Health Nursing Practitioners</i>	6	5:1	<i>Community work specialising in dementia</i>
<i>Academics - Bangor University</i>	6	6:0	<i>Lecturers and researchers in psychology, education and healthcare</i>
<i>Members of the Older People's Commissioner Ageing Well Network</i>	13	6:7	<i>Managers of social care, health and third sector services</i>

The majority of participants in the consultation (68%) were bilingual. The majority of participants in the consultation (92%) believed that there is a difference in the use of services between English speaking and bilingual individuals, with bilingual people tending to be less willing to ask for support.

Three main themes arise from the discussions, namely: **the influence of culture, mental health stigma and the importance of cultural sensitivity.**

## 4. Language or culture?

Healthcare plans in Wales include an option to record the patient's preferred language to ensure health workers offer a service that is most suitable to the individual in their care. The community service delivery team emphasised that those who are providing care need to look at this declaration to ensure that the individual's wishes are respected in accordance with Welsh Language (Wales) Measure 2011 and subsequent More Than Just Words frameworks (Welsh Government, 2012/2016). Communicating with patients in their preferred and most natural language supports health care staff to gain accurate and reliable information about the patient's state of health. It is therefore imperative that cognitive tests are administered in the patients preferred language. The Addenbrooke Cognitive Examination Test (ACE-III, Hsieh, Schubert, Hoon, Mioshi & Hodges, 2013) is a tool used in screening for common types of dementia. The test gives a score of up to 100 (higher scores shows higher cognitive ability). Practitioners discussed a case when a bilingual person completed two tests, the first test in English resulted in a score of 46 and this increased to 65 when offered in Welsh, the individual's preferred language. Although a Welsh translation of the cognitive **assessment** tool kit, including the ACE-III is available, practitioners stated that every person admitted to hospital only receives an English assessment.

## Recommendation 1

Analysis of which cognitive assessment tests are available in Welsh and their use within the health services is required.

## Recommendation 2

An understanding at all levels as to the clinical importance of language appropriate tests is required to avoid inaccurate results. Therefore, qualified staff must be available to deliver the Active Offer of Welsh language services throughout Wales.

# 5. Stigma

Vocabulary can have a significant impact on the confidence of individuals to seek or accept support. Practitioners suggested that the title 'Mental Health Service - Community Psychiatric Nurse' could be a barrier to bilingual residents. A negative perception of mental health is still a strong element within Welsh speaking communities, with staff describing themselves as a 'memory nurse', which seems more acceptable than a psychiatric term and its historical links with mental health units.

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*"People will say: I've never had a problem with my mind - it's my memory!"*

*"The Assembly needs to look at this and nothing will change until it comes from the top by changing the service's name; we specialise in dementia rather than being a small mental health department."*

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(Quotes from the focus group of CPN's)

There was concern that the support available to people affected by dementia is patchy and that there is a lack of information regarding what is available. The North Wales Dementia Network encourages closer collaboration between service providers and people affected by dementia. The Network has developed into a hub of information through meetings and social media within this wider community improving understanding and communication between those working to support people affected by dementia either personally or professionally. This model could ensure that residents are aware of the services that are available to support them in their communities despite the physical and geographical difficulties. Communication between services can improve by combining services under one 'dementia' body.

## Recommendation 3

There needs to be greater awareness of the importance of promoting the bilingual support available to those affected by dementia.

## Recommendation 4

'Welsh voices' must be more prominent when discussing dementia.

## Recommendation 5

The Government needs to establish dementia 'hubs' so that residents can get up-to-date information on what's available for people to live full lives with dementia.

## Recommendation 6

Raising awareness should be in partnership with existing bilingual communities rather than translating an English programme into Welsh, which may not be as culturally acceptable and effective.

## 6. Avoiding accessing support

There was concern that some individuals within the bilingual community avoid accessing timely support. This delay may lead to loss of opportunities to obtain support and advice from experts at a time when they can have more impact. Practitioners believed that a strong element of a traditional fear persists in some Welsh communities that formal social services will remove individuals from their families and communities to a care home. This was also a feature amongst self-employed individuals such as farmers, who often avoid facing their difficulties because of concerns that dementia could affect their ability to earn a living. Community-based practitioners stated that bilingual residents were more inclined to access services after reaching crisis point, by comparison with people who have moved into the area, who seek help sooner.

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*"Welsh people are usually more 'impaired' when accessing day services as they see this as the 'last resort'. Many people fear the diagnosis and are quite embarrassed by having to access a day service and refuse to go to a public party with day care services in case they are seen."*

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A successful example of bilingual community support is the self-funded, volunteer programme in **Waengoleugoed Chapel**. The adapted Chapel house enables volunteers to offer Day care and practical befriending to attendees from three counties. The support is naturally bilingual and is reliant on donations to cover costs. Community dementia services need to be proactive in letting people know that they are there to support them. In the past, a stall in a supermarket, for example, has been a good way for practitioners to raise awareness and engage with the public. Work in schools such as **'Project Anti Glenda'** and the intergenerational programme 'Hen Blant Bach /Care Share' also helps to normalise dementia within bilingual communities.

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*"People are more likely to talk and read information after seeing a presentation and having personal contact after a chat. This goes a long way in a Welsh community and gives the service a face. There are so many things like Merched y Wawr and chapel societies as a way of making connections. Even if only one person thinks 'I thought mam went' - it's worth it, isn't it?"*

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### Recommendation 7

Dementia specialists should give presentations to relevant community-based organisations, e.g. Chapel Societies, Merched y Wawr, Schools and public locations such as supermarkets. Raising awareness can ensure that communities are more inclusive of people living with dementia.

### Recommendation 8

Intergenerational projects can encourage communities to be considerate and inclusive of people living with dementia.

## 7. Raising awareness - GPs

Practitioners agreed that dementia information should be available in all GP sites, encouraging earlier identification of symptoms and referrals for assessment. Practitioners described that GPs classified individuals that moved to rural areas as being at an enhanced risk and consequently referred these residents earlier for a formal assessment. There is a risk in assuming that stable communities and bilingual families can support individuals who have lived in an area throughout their lives. These



assumptions are dependent on historic employment patterns that are less relevant to the requirements of the 21<sup>st</sup> century, adding to individuals' stress and preventing access to services. From practitioners' experience, the awareness of dementia among GPs varies and the demand for dementia services varies a great deal between areas.

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*“We know that the rate of dementia is similar everywhere but the referral rate isn't the same everywhere. Someone could drill down into the demographics, but you must start with the GP.”*

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## **Recommendation 9**

Ensure that all staff in General Practice access a Dementia training package, including locum doctors.

## **Recommendation 10**

Further research is required to understand which areas show low referral rates for dementia assessments with targeted training and awareness raising sessions in areas where referral numbers are low.

## **8. Annex 1. A summary of group discussions with managers in the Older People's Commissioners' Ageing Well Network.**

### **Comments from non-Welsh speakers**

- Disregarding language preference can increase communication barriers
- More Welsh-speaking volunteers are needed in the third sector
- There is a shortage of 'Welsh voices' to describe the dementia experience
- Many people revert to their first language as the illness gets worse
- Memory clinic consultants are unlikely to be bilingual
- The feeling that when services provide Welsh medium services e.g. 'health monitors' that they are not used
- A rural community is more likely to be first-language Welsh
- Isolated individuals may be less aware of the symptoms and unsure how to access help
- Difficulties of not being able to travel to specialist services if transport is not available
- Stigma can be more of a challenge within Welsh communities
- Culture is an important element - "they do things differently"
- The service may be historically be viewed as only available through the English medium

### **Comments from Welsh speakers**

- Welsh culture is reserved, traditional, narrow and perhaps resilient, but this can mean that some avoid accessing care when necessary
- The networks of Welsh speakers are different from those of non-Welsh speakers
- Need to contact a prominent person in the 'Welsh' community to deliver important messages
- Communication can be difficult when care is in a second language or foreign accents. Seeing a 'locum' can affect the confidence of some in communicating, and not knowing the individual's background history can influence the care

### **Recommendations from the Ageing Well Network meeting**

- Important to explain why this is important - not a language choice, but a clinical need
- 'Welsh voices' must be more prominent when discussing dementia
- The importance of effective communication in healthcare
- The messages about dementia must be in collaboration with existing bilingual communities rather than expecting a translated national programme to be acceptable and effective
- Opportunities for children to share time with people living with dementia may tackle stigma and encourage communities that are inclusive of people who live with dementia.

## 9. Annex 2. Recommendations

- 01.** 1. Analysis of which cognitive assessment tests are available in Welsh and their use within the health services is required.
- 02.** An understanding at all levels as to the clinical importance of language appropriate tests is required to avoid inaccurate results. Therefore, qualified staff must be available to deliver the Active Offer of Welsh language services throughout Wales.
- 03.** There needs to be greater awareness of the importance of promoting the bilingual support available to those affected by dementia.
- 04.** 'Welsh voices' must be more prominent when discussing dementia.
- 05.** The Government needs to establish dementia 'hubs' so that residents can get up-to-date information on what's available for people to live full lives with dementia.
- 06.** Raising awareness should be in partnership with existing bilingual communities rather than translating an English programme to Welsh, which may not be as culturally acceptable and effective.
- 07.** Dementia specialists should give presentations to relevant community-based organisations, e.g. Chapel Societies, Merched y Wawr, Schools and public locations such as supermarkets. Raising awareness can ensure that communities are more inclusive of people living with dementia.
- 08.** Intergenerational projects can encourage communities to be inclusive of people living with dementia.
- 09.** Ensure that all staff in General Practice access a Dementia training package, including locum doctors.
- 10.** Further research is required to understand which areas show low referral rates for dementia assessments with targeted training and awareness raising sessions in areas where referral numbers are low.

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