

Health and Wellbeing for Deaf Communities in Wales: Scoping for a Wales-Wide Survey

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Introduction

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Background

Few studies have examined the health behaviours and factors that may help or hinder the d/Deaf population's ability to maintain health in the UK, and none specifically in Wales. In view of the reported inequalities, a better understanding of what helps and hinders d/Deaf individuals' ability to be healthy is needed.

To help inform actions towards a healthier, cohesive and more equal Wales, addressing the aspirations of the Wellbeing of Future Generations Act.

d/Deaf

This report focuses on Deaf people who use and prefer to use a sign language, in this case BSL, and who see themselves as belonging to a Deaf community (i.e. those whose preference is to communicate in BSL and share similar life experiences as a Deaf member of Welsh society).

Background

Funded by PH Wales, we conducted a qualitative pilot study to explore:

- (1) the barriers and enablers to staying healthy in d/Deaf Welsh communities, and
- (2) potential actions for different professional groups (e.g. local authority, planning, health promotion materials, health service (pharmacy, GPs, hospital care)).

Methods Step 1

Comprehensive review of literature

- Due to a lack of literature focused solely on Wales, we consulted literature to identify health and health behaviours and barriers to healthcare of the Deaf population in the UK as a whole.
- Also included evidence from American, Irish, Canadian, Australian and New Zealand Deaf communities.
- Academic journal databases - reports published in English between 1 January 1980 and 1 October, 2018.
- **250 papers and reports** from all over the world. Excluded research and reports that did not deal with the above English-speaking countries.
- **104 papers and reports** being analysed and included in this report.
- Resulted in **seven categories** that formed the framework for the focus groups questions conducted as part of the pilot study

Methods Step 1

Comprehensive review of literature

- Deaf people's **access** to health services, to health providers and to health information is extremely poor (Emond et al., 2015b; Sign Health, 2014).
- **Poor communication** mostly causes this lack of access (Sign Health, 2013; Sign Health, 2014; Kyle et al., 2013).
- As a result, Deaf people are **often underdiagnosed and undertreated** (Emond et al., 2015b; Sign Health, 2014).
- Deaf people also have substantially **limited access to health information** and rely mostly on family members or other community members for their health information (BDA, 2016; Sign Health, 2014).
- **Poor mental health**, such as depression, are more prevalent in Deaf individuals than in the general population (Department of Health, 2002, 2005; Hindley & Kitson, 2000; Kyle et al., 2013; Sign Health, 2014).
- Access to mental health **services tailored to the needs of Deaf people** are lacking (Department of Health, 2002).

Methods Step 2 - 7 categories

Categories and questions

General health:

1. What has helped you stay healthy throughout your life?
2. What has stopped you from staying or being healthy throughout your life?

Health information:

3. How informed do you feel about common health and healthcare issues? *Think about both prevention and treatment.*
4. If you want to learn about a health issue, where do you typically get information?

Accessing health services / primary and secondary care:

5. If you need to access health care services for a physical health issue, where and how would you get help?

Methods Step 2 – 7 categories

Categories and questions

Hospitals and emergencies:

6. If you have a health emergency, where and how would you get help?

Mental health:

7. If you need to access health care services for a mental health issue, where and how would you get help?

Doctor / patient relationship:

8. How do you think GPs or Specialists view deafness and the use of BSL?

Technologies:

9. Are there any technologies that have helped you to access health services?
10. Are there any technologies that you have used that have not worked well?

Focus group sessions

Methods Step 3 – Sessions

- The participants were individually recruited and invited to participate in the interview sessions by the staff at Centre of Sign-Sight-Sound in Colwyn Bay and the Wales Council for Deaf People in Pontypridd, Wales.
- The first group interview was conducted in North Wales in March 2019. Seven members of the North Wales Deaf community participated.
- The second and third group interviews were conducted in South Wales in May 2019, both with three participants.
- All group discussions lasted about two and a half hours.
- Guiding questions were asked in English and interpreted into BSL for participants. All participants responded in BSL, and their responses were interpreted back into English.

Health information

Results & Discussion I

- Poor health literacy among Deaf people constitutes a barrier to allowing Deaf individuals to be proactive about their health and health care (McKee et al., 2014).
- More health information has become available through BSL. (e.g. Sign Health) provides health and overall, health information is available in BSL format, but it is not comprehensive.
- While BDA (2016) received generally positive feedback and a large amount of awareness for their health information videos, this is not always echoed in our focus groups.
- Few participants knew about the resources available, for example, through Sign Health and most participants reported getting their health information informally through their social network.

Health information

Focus group response

*Well normally we ask other Deaf people. What do they know? As a community, we say to each other 'do you know what this means?' So, we check with each other.
(woman, South Wales)*

Health information

Results & Discussion I

- Deaf patients often receive additional health information in written form, for example, through English-language leaflets.
- Deaf individuals are lawfully entitled to reasonable adjustments under the Equality Act (UK Government, 2010), and neither written information nor lip reading are reasonable adjustments.
- Many Deaf people have English as a second language and often have low English literacy rates (cf. Strong & Prinz, 1997).
- A common misunderstanding by health professionals is that Deaf people can read English, and therefore providing written information is wrongly considered a reasonable adjustment.

Health information

Focus group response

“They all think that Deaf people can read, but they don’t realise, for a lot of us, we don’t understand English and it’s really difficult. If I am about to open a letter and there’s information about an appointment, you’re thinking, I don’t really understand the letter. So, you have to ask a friend or family member and it’s private and that’s the problem.”
(man, South Wales)

Accessing health services

Results & Discussion II

- Almost half of Deaf patients have to go in person to their GP practice to book an appointment (Sign Health, 2014).
- Numerous reports of relatives who had to phone GP practices to make appointments for Deaf individuals as well as GP practices refusing to book appointments for Deaf patients who came to the practice in person as the practice only accepted bookings over the phone (cf. BDA, 2016).
- This difficulty in accessing services causes up to 70% of Deaf individuals not seeing a health care provider even though they wanted to (Sign Health, 2014).

Accessing health services

Focus group response

“So, if I want to book an appointment, I physically have to go to the health centre to say that I need an appointment to see the doctor and that I need an interpreter.”

(woman, South Wales)

I can't text them. I would love to be able to text them. It would be so much easier for me. But I can't. I've got to literally walk there and say, 'can I make an appointment for a week or two weeks' time?'

(woman, South Wales)

Access to Interpreters

- Insufficient and inconsistent access to interpreters was probably the most common and pertinent issue raised by participants across the three focus groups.
- 'Having enough time' includes having the interpreter available a little before the appointment and also after the appointment.

Focus group response

“Sometimes I ask for an interpreter, but I don’t have one. So, I use my brother. He can sign so that’s not a problem.”
(man, South Wales)

“I don’t want my daughters with me to interpret. It’s a private appointment.”
(woman, North Wales)

“So, they might say you haven’t given us enough notice to get interpreters. There aren’t enough interpreters here. You have to wait for over two weeks to get one.”
(man, South Wales)

“There are no interpreters over the weekend. It’s not 24 hours a day.”
(woman, North Wales)

Results & Discussion III

Hospitals and emergency services

- Deaf patients generally have poor access to hospitals and emergency services. For example, one study found that BSL interpreters were present at only 17% of GP consultations. This number went down even further with interpreters present at only 7% of hospital emergency consultations (Reeves et al., 2004).
- Our study participants have reported major difficulties in interacting with emergency services and hospitals.
- This starts with contacting emergency services, such as 999.

Results & Discussion III

Hospitals and emergency services

“There are all these questions that they are asking you. It’s not fair for us because hearing people, they’re on the phone, they’re asked questions, and they quickly answer them. Whereas us, we need to read the question, type the answer, and there’s all these questions. And all that we want to be able to say is ‘We need an ambulance. My partner is having a heart attack. Just something short and sweet. Because what’s happening is, we’re panicking, we don’t understand the English, there are all these questions being texted to us, it’s hard enough for us to understand it anyway without panicking at the same time.”

(woman, South Wales)

“I already said to them ‘I don’t understand your words’. And they kept texting the same questions again. And I kept saying to them ‘I don’t understand you. I’m Deaf.’ [...] They just refused to accept that I couldn’t understand them.”

(woman, South Wales)

“The best way to do this is just dial 999 and just leave your phone because suddenly everyone comes to your doorstep wanting to know what’s wrong. That’s easier for us. That’s what I would do. [...] As a Deaf person, you can say ‘Well, I’m sorry, I can’t ring you. I can’t understand your texts’.”

(man, South Wales)

Results & Discussion IV

Mental health

- Mental health problems arise from differences in individual vulnerability, resilience, environmental risk, and environmental protection, as well as adverse life conditions (cf. Øhre et al., 2011).
- Deaf adults and adolescents have a higher incidence of mental health problems than the general population (cf. Bridgman et al., 2000; Brown & Cornes, 2015; De Graaf & Bijl, 2002; Department of Health, 2005, Fellingner et al., 2005; Kvam et al., 2007, see Fellingner et al., 2012 for an overview) irrespective of degree of hearing loss (cf. Fellingner et al., 2008; Dammeyer, 2010; Stevenson et al., 2010; Hintermair, 2007).
- There is a lack of Deaf mental health professionals, “who have the language and empathy of being a member of the same culture and community” (Klein, 2011, p. 65).
- The Department of Health (2005) also notes the striking scarcity of Deaf people employed in mental health services.

Mental health

Results & Discussion IV

"I would never have a Deaf person counsel me because the community is so small."
(woman, South Wales)

"Yeah you want your privacy. You don't want [...] to have other people know what's going on."
(man, South Wales)

"I'm happy to see a counsellor that is hearing with an interpreter. They did offer me a Deaf person who was a counsellor, but I refused. I refused it because the Deaf community is too small. I didn't want them to gossip."
(woman, South Wales)

- The responses from the group interviews reflect patients' wishes to avoid gossip and a wish to engage with mental health service providers that are not part of their local Deaf community.

Doctor-patient relationship

Results & Discussion V

- When Deaf individuals do see a health care provider, the interaction is often not satisfactory and Deaf patients experience fear, mistrust, and frustration in health care settings (Steinberg et al., 2006).
- Effective interaction with signing professionals or interpreters improves patient satisfaction and increases the use of preventive services among Deaf people (MacKinney et al., 1995; Breen 2015; Witko et al., 2017; Dykes, 2016; Finger Lakes Health Systems Agency, 2004).
- Deaf awareness training, especially for front line staff, should be standard (cf. Department of Health, 2005), especially as the receptionist was often seen by Deaf people as the biggest barrier to accessing health care (cf. NHS Wales Centre for Equality and Human Rights, 2018).
- It is important that health care providers recognise and understand that linguistic and cultural differences are an important part of healthcare and that this applies to sign language communities as much as to other minority language groups.
- Witko et al. (2017, p. 10) write that "when Deaf people perceive this recognition, they describe feeling more satisfied with a health consultation even without an interpreter".

Results & Discussion V

Doctor-patient relationship

“Also, with the hospital, we’ve got the fact that we’re Deaf on our records, but the nurses and doctors need to learn a bit more about Deaf awareness, so that should be part of their training. It’s important that everybody has it, all members of staff, so they know if there’s a Deaf patient – just something basic, so that they know how to sign ‘How can I help you?’ Just basic signs. It would be so easy for them and then we could say that we need an interpreter.” (woman, South Wales)

“I want more people to have awareness of us as Deaf people.”
(man, South Wales)

(About doctors)
“Sometimes the attitude can be difficult.”
(woman, North Wales)

(About doctors)
“Sometimes you feel like you are easily ignored being a Deaf person.”
(woman, North Wales)

“I always feel like Deaf people are put last.”
(woman, South Wales)

Key considerations and potential actions

Health information

- Both health and care professionals and Deaf communities need to be made aware of health related information developed specifically for Deaf patients, and where to find it.
- Practitioners need to be aware that many Deaf patients cannot read English written information material. When possible, links to health information in BSL should be provided.

Health care

- All staff should undergo Deaf awareness training, select staff members should have basic BSL skills, and all staff should be aware that BSL is not a signed form of English.
- Patients should be able to make appointments through various means, not just over the phone. Online and texting services are already available but should be made more accessible to Deaf patients. Online interpreter services to book appointments also exist, but awareness of these services in Deaf communities needs to be increased.

Interpreters

- More Registered Sign Language Interpreters (RSLI) are needed, especially those trained in specialised health care settings.
- Reliable and consistent access to interpreters needs to be 24/7/365, for example, through an on-call system similar to that for doctors.

Future directions

- The responses, reflections and experiences conveyed by the pilot study participants however paralleled and often concurred with many of the issues faced by Deaf communities in the UK, USA, Ireland, Canada, Australia and New Zealand.
- These findings clearly suggest that a more detailed population specific survey is needed to assess how members of the Welsh Deaf community specifically interact with their particular health care services, within their respective communities, and what the state of their wellbeing is.

The next step: Importance of co-production

- **Pilot project highlighted the importance of engagement and building personal relationships with the staff of d/Deaf and Hard of Hearing support / service agencies (i.e. the Centre of Sign-Sight-Sound in Colwyn Bay and the Wales Council for Deaf People in Pontypridd), with BSL interpreters and with members of Welsh Deaf communities.**
- UK have enacted laws prohibiting discrimination based upon 'disability' and legally ensure that all qualifying citizens have appropriate and supported access to healthcare services; however, it is clear from the focus groups' responses and experiences that these mandated requirements are often not being met for members of the Welsh Deaf community.
- Evidence also strongly suggests that the Deaf community in Wales is also beset by a number of cultural, linguistic, logistical and institutional issues that continue to have a negative impact on this community's health, wellbeing and quality of life.

The next step: Importance of co- production

- In addition to a Welsh Deaf census a more comprehensive follow-up study is therefore warranted to identify the barriers and enablers affecting the Deaf community across all of Wales, so that current practices and policies can be adjusted and/or improved to better serve this important minority community.
- This is our one of our goals (Bangor University, University of Graz & Public Health Wales) going forward. We are working to secure funding for a comprehensive follow-up survey and census
- This pilot study report is available in PDF formant and in BSL video format here:
- <http://deaf-communities-wales.bangor.ac.uk>
- Hard copies are available upon request

The next step: Importance of co- production

Additional research objectives include:

- Project entitle 'd/Deaf identity in Wales: Understanding a unique cultural and linguistic minority group'
- Holding a series of qualitative video-recorded interviews with Deaf participants across Wales to discuss aspects of Deaf culture, identity, community, and life experiences.
- The development of an on-line and video-based Welsh BSL sign dictionary
- To also conduct the first ever Welsh BSL dialect survey.
- To create an online Welsh BSL corpus (with search and tagging features using ELAN software package) similar to the British Sign Language (BSL) Corpus at UCL.
- Hope to provide funded opportunities for Deaf Welsh PhD students

The next step: Importance of co- production

All of this will require community involvement, engagement and support.

This will be the website / portal for these projects:

<http://deaf-communities-wales.bangor.ac.uk>

Also establish an email contact list, Facebook page and related social media to keep the entire community up to date and informed as to the project, research outputs, events, calls for participants, and any other developments

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Thank you for your time, attention and support!

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