

MHB009 - Grŵp Iechyd Meddwl a Lles Pobl Fyddar Cymru Gyfan

Senedd Cymru | Welsh Parliament

Bil arfaethedig – Datblygu'r Bil Safonau Gofal Iechyd Meddwl (Cymru) |
Proposed Development of the Mental Health Standards of Care (Wales) Bill

Ymateb gan: Julia Terry, Grŵp Iechyd Meddwl a Lles Pobl Fyddar Cymru Gyfan |
Evidence from: Julia Terry, All Wales Deaf Mental Health and Well-Being Group

Enshrining overarching principles in legislation

Question 1: Do you think there is a need for this legislation?

Can you provide reasons for your answer.

We are aware that many populations within Wales do not have equity in terms of mental health services provision. There is little parity for certain groups in terms of the provision of physical and mental health services. The communities we wish to highlight to you are Deaf populations, particularly Deaf British Sign Language (BSL) users. Since 2006 we have been campaigning for change. Wales are the only UK country with no Deaf mental health service. Deaf people have twice the risk of mental health problems than hearing people.

There is certainly a need for this legislation to ensure people in Wales have more choice and influence over their treatment and receive the dignity and respect they deserve. The measures proposed within the Bill will also strengthen the patient voice, and it is particularly Deaf populations that we wish to highlight.

The All Wales Deaf Mental Health and Well-being Group collaborated with Deaf and hearing professionals to compile a report to provide an overview of the health inequalities experienced by Deaf people in Wales in relation to mental health service provision. A literature search was conducted, then data gathered from case studies from Deaf people and British Sign Language (BSL)/English interpreters, evaluations of mental health promotion initiatives involving Deaf people, statistics from Sign Language interpreting agencies, and information from UK specialist Deaf mental health services. We then published our report Deaf People Wales: hidden inequalities, and launched this at the Senedd in May 2022.

Question 2: Do you agree or disagree with the overarching principles that the Bill seeks to enshrine?

The overarching principles of choice and autonomy, least restriction, therapeutic benefit and recognising and respecting people as individuals is a fundamental right for all people.

We are aware of many examples in Wales where these principles are not adhered to by services, meaning a challenging, inadequate and disappointing patient experience. Sadly this often leads to people not seeking help, meaning not having treatment and being at increased risk of their mental health problems deteriorating further.

Specific changes to existing legislation

A. Nearest Relative and Nominated Person

Question 3: Do you agree or disagree with the proposal to replace the Nearest Relative (NR) provisions in the Mental Health Act 1983 with a new role of Nominated Person?

Can you provide reasons for your answer.

A nominated person may go some way in making sure that patients have choice and that their views are respected and assumptions are not made.

Please do be aware that for many Deaf people, the arrangements, booking and provision of BSL/English interpreters is often a challenging experience for Deaf people. This leads to family members being inappropriately asked to interpret at a time when a person is extremely vulnerable with many potential implications about treatment, freedoms and legal issues in the context of mental health legislation. There have been recent news items in March 2024 about this, and how many populations are disadvantaged by the lack of interpretation services.

We are aware of challenges around who the Nominated person could be – skills /experience/ / availability /training and who will oversee quality and outcomes ...measure / monitor this – similar to the current RPR role within the DOLS procedures and there are very few people with the skills training etc to take this on within Wales even now. We note the importance of accuracy of diagnosis and how Deaf people’s mental health conditions may be difficult to accurately diagnosis without the relevant training and knowledge about language context.

B. Changing the criteria for detention, ensuring the prospect for therapeutic benefit

Question 4: Do you agree or disagree with the proposal to change in the criteria for detention to ensure that people can only be detained if they pose a risk of serious harm either to themselves or to others?

Can you provide reasons for your answer.

This would depend on the context, but all assessment and treatment information needs to be accessible so that patients and families are and feel fully informed. It is access to effective communication that is often a major problem. Please note we have the British Deaf Association reviewing Welsh Government policies and also revising the 2013 Accessible standards to communication due to the low equity currently provided.

Question 5: Do you agree or disagree with the proposal to change in the criteria that there must be reasonable prospect of therapeutic benefit to the patient?

Can you provide reasons for your answer.

Again, it would depend on the situation, but it comes back to equity of provision and communication. We have been wanting the number of Deaf professionals to provide treatment in Wales to increase. Any Deaf for Deaf services are dependent currently on Health Boards agreeing to funding.

Even having some services tailored to Deaf people's mental health in Wales would be a start.

C. Remote (Virtual) assessment

Question 6: Do you agree or disagree with the proposal to introduce remote (virtual) assessment under 'specific provisions' relating to Second Opinion Appointed Doctors (SOADs), and Independent Mental Health Advocates (IMHA)?

Can you provide reasons for your answer.

Remote assessments in some circumstances can be appropriate, but need to be as accessible as possible for all individuals, please do ensure consultation about making these accessible with captions, and BSL/English interpreters.

Professionals may not always realise that when assessing a Deaf person the nonverbal elements and overall communication and use of the entire body are a key part of assessment, and when someone is a Deaf BSL user then only the person may be visible from the waist up in a remote online assessment, and in-person assessments should be more accurate.

Practitioners and people with communication requirements prefer Face-to-Face interpreting and have provided consistent feedback on the drawbacks to telephone and remote interpreting that body language cannot be interpreted or conveyed effectively, that there can be challenges with:

- poor sound quality
- hardware isn't always available or suitable
- it can take longer using the phone
- using a loud speaker could compromise confidentiality
- physical examinations are particularly difficult using the phone
- it's very impersonal and doesn't facilitate building trust or rapport
- video screens can be a distraction from the content of the appointment
- people are less likely to open up about issues

Interpreters have reported that they are unable to “add value” to the interpreting assignment when it takes place over the phone or by video; telephone and video sessions do not have space/time for informal pre and post sessions between the service user and the interpreter that would usually take place during waiting time.

It was during this waiting time that trust and rapport are established and built so that interpreters are able to gain a better understanding of the service users' additional needs and give appropriate factual information, signpost to other organisations, and refer into support services such as social prescribing, advocacy and befriending. Even asking simple questions, such as if a person needs help booking a vaccine appointment, can be difficult to fit into a more structured and focussed interpreting session over the phone or on a remote platform.

D. Amendments to the Mental Health (Wales) Measure 2010

Question 7: Do you agree or disagree with the proposal to amend the Measure to ensure that there is no age limit upon those who can request a re-assessment of their mental health?

Can you provide reasons for your answer.

No age limits means that people have more choice and are less restricted by service bureaucracy. Someone who knows their mental health and triggers, and is of a certain age and knows the need to self-refer needs to be taken notice of.

Question 8: Do you agree or disagree with the proposal to amend the Measure to extend the ability to request a re-assessment to people specified by the patient?

Can you provide reasons for your answer.

If a person specifies a particular person for assessment, it would likely be because that is a trusted Mental health professional that they know and have been treated by in the past. There are decades of mental health research showing the importance of trusted, professional therapeutic relationships, so yes agree the opportunity to request a re-assessment with people specified by the patient could be very useful for all involved.

General Views

Question 9: Do you have any views about how the impact the proposals would have across different population groups?

Potentially any changes that make mental health services in Wales more equitable and more accessible are very welcome. We are aware of the impact of the current lack of service provision for Deaf people in Wales, particularly those requiring in-patient hospital provision and the need for patients having to travel to England for treatment. We wish to highlight the lack of Deaf awareness training that health and care staff have, and also the lack of specialist Deaf mental health provision.

Question 10: Do you have any views about the impact the proposals would have on children's rights?

Deaf children in Wales have no Deaf CAMHS services, and this is not on people's radar. Children who are Deaf have no Deaf schools in Wales, and the number of Teachers of Deaf children and young people are reducing. Children and their families experience many barriers that impact negatively on their lives and their future, and often this leads to increased mental health problems.

Question 11: Do you have any general views on the proposal, not covered by any of the previous questions contained in the consultation?

As the All Wales Deaf Mental Health and Well-being group we are an active group of Deaf and hearing professionals working in Deaf charities, Health Boards, universities, Public Health Wales and the third sector. We launched our report 'Deaf People Wales: hidden inequalities' at the Senedd in May 2022, and continue to campaign for changes to mental health services and to see improvements made for Deaf people who are an ignored population at risk of not receiving services. The recommendations from Deaf People Wales were:

- Increase health and care workers' knowledge of basic BSL and how to book Sign Language BSL/English interpreters
- Primary care staff to have increased knowledge of available mental health services for Deaf patients and to signpost
- Deaf patients can directly go to Deaf counselling services
- Basic training around Deaf issues for all health and care workers
- An accessible helpline and signposting service would direct individuals, families and workers to timely advice
- Monitoring effectiveness of Health Boards' delivery of All Wales
- Accessible information standards
- Improve access to information for BSL users by adopting same rights as Welsh speakers to services
- Re-establish links with Deaf CAMHS

As a group we are increasingly publishing research about the state of play in Wales as we have several publications in peer reviewed academic journals regarding evidence of the situation in Wales. It is our view that this evidence, along with the Cross Party group on Deaf issues, the new BSL Policy advisor and the Disability task force will be of significant help to you with your bill and plans moving forwards, please do engage with us.

Part of the rationale behind your consultation takes into account the need for High quality specialised services. We need to ensure that we have a joined-up approach to commissioning to utilise the benefits of nationally, regionally or locally commissioning services, where appropriate, and to ensure it is done in partnership with local services and Deaf communities. The effective commissioning of services will enable us to ensure we have in place high quality, best outcomes and best value services and reduce unnecessary variation across Wales. We are aware that currently Deaf people needing mental health inpatient admission have to travel to London, or Manchester, which is many miles from their family and friends. Also on their return to Wales there is no accessible follow up service for them, so there are issues about isolation, accessibility and a lack of recovery and support services.

Useful references from our group members:

Foltz, A., Cuffin, H., & Shank, C. (2022). Deaf-Accessible Parenting Classes: Insights from Deaf Parents in North Wales. *Societies*, 12(4), 99.

Terry, J., Meara, R. (2023). A Scoping Review of Deaf Awareness Programs in Health Professional Education. *Plos Global Health*. Under review

Foltz, A., & Shank, C. (2020). Deaf Sign-Language Using Patients' Experiences in Health Emergencies in Wales: Perspectives for Improving Interactions. *Frontiers in Communication*, 5, 572855.

Terry, J., Meara, R., England, R. (2023). "They still phone even though they know I'm Deaf": exploring experiences of Deaf people in health services in Wales, UK. *Journal of Public Health*. Under review

Shank, C., & Foltz, A. (2019, November). Health and wellbeing for deaf communities in Wales. Scoping for a Wales-wide survey. In *It Makes Sense Conference: Sensory Loss Awareness Month*. Bangor University.

Shank, C., & Foltz, A. (2018). Healthcare barriers and enabler affecting the Deaf community: A comprehensive review of literature and meta-analysis report.

Terry, J, Rance, J (2023). Systems that support hearing families with deaf children: A scoping review. *PLoS ONE* 18(11):e0288771.

<https://doi.org/10.1371/journal.pone.0288771>

Terry, J. (2023). Enablers and barriers for hearing parents with deaf children: Experiences of parents and workers in Wales, UK. *Health Expectations*.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.13864>

Terry, J. (2021). Developing networks to improve practice, policy and education with Deaf communities. *Clinical Psychology Forum*, No 348, December 2021. Special issue: Deafness and hearing loss

Terry, J., Redfern, P., Bond, J., Fowler-Powe, M., Booth, C. (2021). *Deaf People Wales: Hidden Inequality*. All Wales Deaf Mental Health & Well-Being Group. June

2021. <https://bit.ly/36ao3IE>

Terry, J. (2021). Examining interventions to improve young deaf people's mental health: a search for evidence. *British Journal of Child Health*, 2(2), 78-84.

Wilks, R. (2024). 'Unseen and Unheard: How the Future Generations Act is not Addressing the Needs of the Welsh Deaf Community.' (Submitted to Disability & Society).