

Mental health inequalities

Engagement Findings

March 2022

1. Background

1. In February 2022, the Senedd's Health and Social Care Committee launched an inquiry into Mental Health Inequalities in Wales.
2. The Citizen Engagement Team supported the Committee by facilitating a series of focus groups with groups of people who were impacted by this inquiry. This report summarises the Citizen Engagement Team's findings.

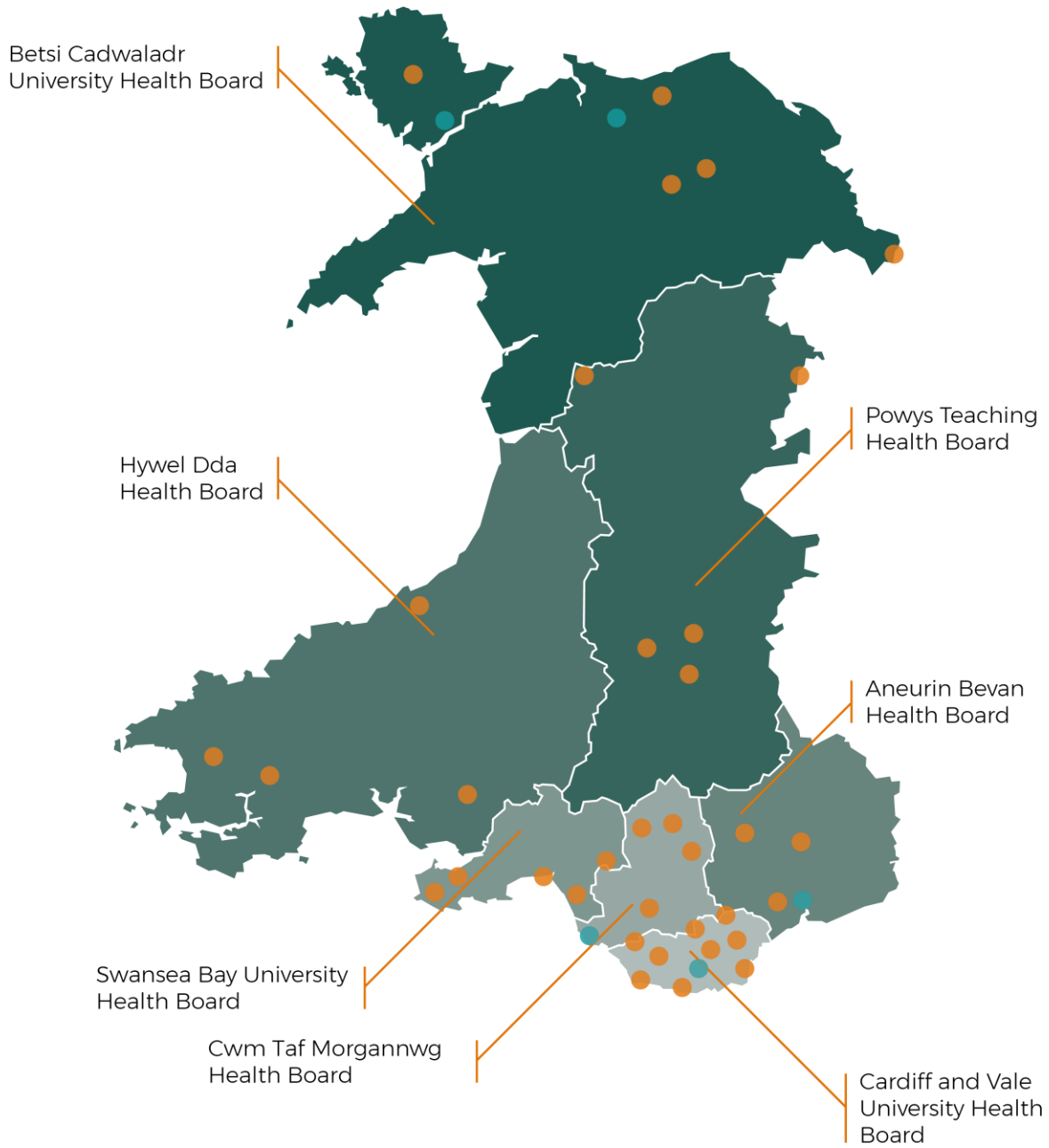
2. Participants

3. The Citizen Engagement Team aimed to ensure that the groups identified in the terms of reference of the inquiry were represented within the series of focus groups, i.e. older people, people with autism, people living in poverty, black adults, LGBT+ people, deaf people, children and young people with a learning disability, and people with severe and enduring mental illnesses.
4. Both men and women were represented within the focus groups.
5. The Citizen Engagement Team worked in partnership with relevant organisations to source participants and ensure that they received appropriate support and advice throughout.

77 people from across Wales took part in the focus groups.



Location of Participants



● Location of virtual Focus Group Participants

● Location of face to face Focus Groups

Organisations:

- Adferiad
- Fair Treatment for the Women of Wales
- Mind Cymru
- Llamau
- Age Alliance Wales
- Age Cymru Powys
- Autistic UK
- Parents Voices in Wales
- Barnardo's: Newport Young Carers
- Golau project Ynys Mon
- Men's Shed Bridgend
- Men's Shed Rhyl

6. We would like to thank all the participants for taking part in this inquiry.

3. Methodology

7. Between 1 February and 1 March 2022, the Citizen Engagement Team facilitated 13 focus groups and 2 one-to-one interviews with participants from across Wales. 8 focus groups took place online and 5 took place face-to-face.

8. The objective of the engagement was to gather the views and experiences of people from across Wales who have been impacted by mental health inequalities.

9. The format of engagement was largely comparable between sessions but varied slightly to meet participants' needs. Some focus groups were attended by members of the committee.

10. Participants were asked to discuss the following:

- The factors that contribute to poor mental health.
- The key issues faced in accessing mental health support and how effectively existing services meet those needs.
- How mental health services could be improved.

11. Notes from each session are available on request.

4. Key Themes Emerging

GP Services

12. All focus groups said that the level of service provided by GPs played a significant role in their poor mental health.

13. Issues with GPs consisted of difficulties in getting appointments, poor attitudes of receptionists, and poor service provided post-appointment.

"I have had self-harm issues my entire life. I finally plucked up the courage to go to a GP. I had to explain what I was thinking. The GP was dismissive and couldn't wait to get rid of me – I walked out and that was that. There is no clear pathway."

"Autism is still classed as grounds to be able to section people – when you have a GP who doesn't understand autism and they have that power it's really scary."

14. Many participants across different audiences pointed out the difficulties faced when communicating with a GP receptionist in attempting to access a GP.

"Getting to the front line to GPs is difficult. Getting past the receptionist or front line staff is so hard. Front line staff that just can't communicate with you and that is particularly common with autistic people."

"There is a big issue out there with GPs. Receptionists are generally poor and I have several examples of our young people being treated appallingly."

"We had an instance where a young person was going to take her own life. Between 9 am and 4:30 pm we could not get an appointment with the GP. The police, nurse from CAMHS all phoning and couldn't get anywhere. The young person was having to phone the GP themselves, trying to speak to a receptionist who was refusing point blank to accept the person was in crisis."

"Receptionists! Where do I start? I have broken down crying in front of them, just asking 'why are you treating patients like this?' It's soul-destroying."

15. Participants explained that the standard of service provided by GPs when dealing with the issue of mental health is also a cause for concern. Several participants noted their belief that GPs were not trained in mental health support. Participants commented that GPs appeared not to look at the overall picture and preferred to prescribe medication, rather than offer alternative support and referrals.

"Tablets are not the only solution to all of this – feels they do that and off you go, just to tick a box and get rid of you... then on to the next one."

"GP doesn't help. For example, you say you get bullied and they assume if that stops then I will be magically better. They don't seem to understand the wider issues. It's pointless talking to them."

"There is a lack of information on relevant conditions – I give up telling them what's wrong, I might as well keep it in. My best mate is more helpful than the doctors, at least she listens and takes me seriously."

'The general feeling I see is that people with extreme mental health issues is that you go to GP and you get shoved on medication, here is a pack of pills and be on your way

"GPs are trying to treat everybody the same and everyone isn't the same. They read the books but they aren't trained and give you terrible service."

The Pandemic

16. Across all focus groups, the pandemic was seen as having a detrimental impact on participants' mental health. However, a majority noted that the pandemic **only emphasised the inequalities that already existed within mental health**. Participants further illustrated that the pandemic had brought its own unique mental health problems.

"Services were hard to access before the pandemic, but things have got worse. It feels like in some cases that COVID has been used as an excuse to further let people with mental health problems down."

"We are all tactile people and that lack of contact with family, any interaction was removed during Covid – it caused havoc with my mental health."

"Covid has just exacerbated these key issues, the lack of opportunities, family issues, family breakdown. The factors are the same for our young people but they have been compounded."

17. Participants highlighted some of the unique mental health issues that emerged from the pandemic, including a lack of opportunity to grieve properly and difficulties obtaining information from media outlets.

"Covid is dreadful. Me, my friends, people I know all feel the same. One of my older friends taped all the seals on the windows and doors, she is so terrified that the virus will get through any gap. Her mental health has suffered badly."

"I just had to watch my aunt dying in another country and I have lost multiple friends to Covid. There is a wider issue that Covid has not let people grieve properly. We have whole communities in my areas affected by this. It's a huge issue."

18. Participants also noted some positive outcomes in relation to talking openly about mental health and the positive impact exercise can have on mental health.

"Other people now seem more comfortable with talking about their negative mental health which helps with the stigma, and another thing was that the lack of services showed me that I could cope ok without them."

"Working from home has helped. Having the option to be able to do college work from home when I am having a bad day has helped my recovery greatly."

Stigmas and Negative Perceptions

19. The word 'stigma' was used frequently by participants when talking about their experiences when discussing mental health. **Participants felt perceived stigma was an issue when attempting to gain support from the NHS.** Participants also noted that wider societal stigma still exists when discussing the topic of mental health.

"We need to remove the Mental Health stigma and treat it like a physical illness. If you have mental health problems then there are solutions and services that we need to be made aware of."

"There is a stigma involved when discussing Mental Health, even within the NHS: We are dysfunctional, we are broken, blah blah, blah. It's exhausting."

"I have a diagnosis that carries a lot of stigmas. I have to be careful how I communicate, I need to watch my tone. If I say I am struggling then the support isn't there for me."

"There is a big stigma in general around Mental Health – we need to change the language around MH, we are not on the verge of a crisis we are in one."

20. Participants noted that stigma can form around age, gender, and health conditions as well as a previous history of mental health issues.

"It feels like it's not just within health services but that in Britain nobody likes older people! The pension triple lock, not being taken seriously when talking about mental health, it's ageism."

"Men hold it in for a lot longer, till that point when you have to burst. We don't recognise it. There is a stigma. It's hard as a man to diagnose depression, what is it? I had no idea at the start"

"As soon as they hear that young people are from supported housing there is a stigma. You can ring the police and it's the attitude of 'oh not them again' – it would be different if it was a middle-class white kid from Pontcanna – that stigma is clear as day,"

Neurodiversity

21. Participants noted in several groups that **people with neurodivergent conditions experience difficulties in accessing services**, which plays a role in the development of poor mental health.

"The treatment for neurodevelopmental disorders feels like it's a real issue for Mental Health – inequality of access to neurodiversity services and where it sits. In Powys, it sits within Mental Health Services but in other areas, it doesn't."

"I have poor mental health as a result of my child having poor mental health. My child's mental health is linked to late diagnosis of their neurodiverse condition."

"When it comes to my ADHD, I feel that I have been neglected by the system. There is a ridiculous lack of understanding within the NHS and the system isn't fit for the support we need."

22. Many participants noted how a **lack of support and understanding from NHS services** led to repeated anxiety around having to hide or 'mask' their conditions. Several examples illustrated the issue of late diagnosis of a neurological condition, and the need for the NHS to take a whole person approach when tackling mental health issues.

"I have a poor relationship with my GP. The doctor labeled me as threatening as I was rocking when I was stressed and nervous. Because they labeled me, I have been terrified of trying to access support and my mental health has deteriorated so much."

"My mum has been trying to get me diagnosed with ADHD since I was born and I am still waiting. I haven't had any help for it and I still struggle."

"It's hard to get stuff diagnosed, GPs haven't got the knowledge. I have been in front of so many doctors who said 'yep you have ADHD' but he couldn't officially diagnose me as he was not allowed."

"The interplay within ND and mental health and chronic illness, it's all such a complex picture which is hard to unpick but our health professionals' starting point needs to be acknowledging those complexities. Everyone within the

system is just looking at things through a single lens. Every pathway looks at one thing at a time. We need to look at the whole person as a starting point. Until we do that, people (especially women) will be constantly let down by the system."

Social Prescribing and support of the third sector

23. Focus groups discussed the importance of social prescribing in supporting patients with poor mental health. Some participants had positive experiences through social prescribing, others were unaware that it was an option and had never been referred to these services.

"Pre pandemic I was in England and the GP surgeries were turning into hubs with lots of services. That as a way forward feels good. Right now there is nothing in my surgery – no social prescribing at all. Making GPs less venerated and more part of the community is the way forward."

"We need to talk about social prescribing. GPs shouldn't just be prescribing antidepressants. Young people don't know they can access free gym passes for example and they don't get told this. My learners don't have a clue it's an option – it needs to be shared more."

"Social prescribing is a good way of linking some key issues together but is it sustainable? Funding seems a constant issue."

24. There was widespread praise for third sector organisations across focus groups. Participants praising the support they had received and felt the need for further support to enable third sector organisations to provide a consistent long-term service:

"Looking outside of the NHS, I have to say that Time to Change Wales changed my life. I felt a shell of myself. With their support, I found my voice and I found my people."

"If it wasn't for Men's Shed and my dog then I wouldn't be here – simple as that."

"Mental Health Services of course are important but we need more money to support young people. We need more youth workers. Social prescribing is crucial in all of this and more needs to be done!"

"Everything is a project, short-term funding, a new idea... my child is not a guinea pig. We need a consistent long-term service that works."

Waiting Times

25. Several participants noted the detrimental effect long waiting times had on their mental health, and that the issue of waiting times is prevalent across health services.

"There are extremely long waiting lists. The pandemic made them longer. The stress of being on a waiting list and constantly not being believed on top of this and parents can be referred to social services."

"Waiting times are years! What's the point of seeing a GP for a problem when you know you will just be on a waiting list for a year or more?"

"Waiting times are 12 months, it's not acceptable. Hearing for example is so linked to your mental health, it leaves you isolated and just wanting to turn into a hermit. I know eyes are prioritised over ears and that's not right. The service is not a priority and it's not right."

"In 2019 I was referred to transgender services (gender clinic) that were 2 years pre-Covid and now it's another 2 years apparently. At a crucial stage in my life, I have to hang around for 4 years."

"Waiting lists are not acceptable for services. You cannot leave people languishing on mental health waiting lists long term when people can't function."

A need for improved mental health training for the NHS, public services, and schools.

26. Focus groups felt that there is a lack of training amongst health professionals in how to support people with mental health issues.

27. Participants spoke of negative experiences they had with the NHS, police, and schools. Participants feel that there is a lack of training and understanding of certain conditions. Within these organisations.

28. Many participants also spoke about the need for successful early interventions in schools.

"The lack of training around neurodiversity is terrible. This goes back to the school teachers needing additional training."

"Starting in schools, there needs to be a focus on wellbeing and enabling children and young people to develop strategies where they can become more resilient."

"Schools are crucial in solving this. Right from the start, the staff is not trained for this. Front line staff who are dealing with these young people who are in crisis have no training, no support."

29. Similarly, several focus groups noted a problem with the training given to NHS services. Participants felt that there is a lack of understanding of patients' conditions. The need for greater co-production was also highlighted.

"We need more neurodiverse people who are offering services and also have them to train up these staff who are on the front line. Going to people who can't understand our neurology, who have just learned things from a book and quote theories that have long been debunked is not good enough."

"I am autistic and one of the barriers is that I know more about my illness than 'experts'. Unfortunately, unless you turn up to a crisis team at a terrible point, they don't consider you in danger enough to listen to. Women are constantly patronised by male health professionals. It seems the knowledge is not there and there is a wide-scale need for change in training."

5. Other issues emerging

30. Below is a summary of further issues discussed by participants, that were specific to the particular demographic within the group.

Financial impact

31. Anxiety due to financial problems and fears over the cost of living was a theme discussed by some participants. Participants explained that this added anxiety exacerbated existing mental health problems.

32. In particular, issues surrounding the Department of Work and Pensions (DWP) and the difficulties in securing Personal Independent Payments (PIP) were seen as having an impact on poor mental health.

"EMA (education maintenance allowance) doesn't provide enough money. Not having any money is not great for Mental Health. Cost of living is a huge stress for me and things are just getting worse."

"PIP stresses my mum out and it's a domino effect. PIP is very difficult to get. My mum feels like she is being interrogated, it makes me feel awful."

"Every time I speak to the DWP I feel like I am a fraud to them. The conversations are more like an interrogation and you are made to feel like a strain on the system."

"I hate to admit that living in poverty has an impact on my mental health, but it does. All the stress, anxiety, worried about missing days in work and not getting paid. It has taken me to some dark places."

Impact on young carers

33. Some younger participants, who are also carers, spoke of the impact caring for a family member has upon their mental health.

"College takes up loads of time. I come home and then I care, and then more college time – it's easy to neglect yourself. No one understands how hard it is to balance everything."

"I come home from college at 7 pm then do mum's meds, help her shower... By the time she is in bed, I am up till 4 am trying to finish work. I get barely any sleep... it's hard and my mental health suffers."

"I feel guilty that I am getting the help here. I didn't even know I was caring as it's something I have done since I was young. My stepdad doesn't understand caring, he doesn't understand mental health – I feel he needs help more than me and I feel odd I am the one getting it."

Inequality of accessing services

34. Participants highlighted the difficulty in accessing specialist services, including mental health services. This included the difficulties in accessing certain services within health boards in Wales but in some cases also meant that people had to travel over the border to England.

"Lack of services means there is a dearth of them and they are not accessible if you are in the wrong health board in Wales or they're over the border. In Wales, there are no inpatient clinics for eating disorders where 70% of them are female."

"There is a lack of joined-up services. It's a constant battle trying to get services to talk to each other. No one wants to take responsibility."

"I think more equality of access is needed as it feels like it's a postcode lottery. I would have had to travel to go to England to a specialist mother and baby unit. It's not fair that based upon where you live that you can or can't access specific services."

"I think the easiest thing to be said would be, what mental health services? They might as well not exist in Wales for all the good I think they do"

Media and Social Media

35. The impact of the media and social media both came up in specific focus groups. When talking to **older people**, there was discussion around the negative impact that 24/7 news had for people in isolation, whilst **young people** highlighted how social media means they are never able to switch off.

"Social Media is a big problem. It's a big part of my and my friend's life. I am never away from issues plus there are a lot of creepy people on there constantly trolling. It's so easy to get targeted."

"Life on there is just glamorised and it forces self-esteem issues on young people, which isn't exactly ideal for your mental health is it?"

"The TV is a friend for some older people – but I do think that this 24/7 coverage of negativity has had a hugely detrimental impact on the mental health of older people, COVID 19, now the news in Ukraine, some people just can't cope with it."

Isolation and loneliness

36. Some focus groups mentioned the impact that isolation and loneliness had on their mental health. **Men** and **older people**, in particular, noted this issue during their focus groups, but **young people** as well spoke about how their mental health was improved by the support networks they had in their lives. It was also noted that poor public transport had exacerbated some people's sense of isolation.

"Socialising has gone now. Nobody says hello to you in the morning, times have changed. It is easy to feel isolated and lonely."

"If I sit in the house then I mope and think too much. If I am busy and doing stuff then it goes to the back of my mind"

"If you find it difficult to take care of yourself, then how can I take care of others? I hate the thought of doing this alone, we are all in a WhatsApp group together and that support I get is a huge help."

" The cost of traveling has kept going up and up alongside a reduction in services. I feel that my world has shrunk, loneliness has crept in and my mobility has suffered."