



Mind Cymru's response to the Health and Social Care Committee's Inquiry into Supporting People with Chronic Conditions

Overview

We welcome the Health and Social Care Committee's inquiry into supporting people with chronic conditions. Mental health is a unique area of analysis within the context of this inquiry. It often comes hand in hand with poor physical health, but it can also be a chronic condition in itself.

Parity between physical and mental health has often formed part of Welsh Government strategies. There is clear evidence that poor physical health and physical disability significantly increases the risk of developing mental health problems, and vice versa. Wales has the highest rate of disability in the UK, with nearly one third of adults affected by conditions such as diabetes, arthritis, heart disease, or asthma¹. The recent Diabetes UK report, 'Diabetes Can't Wait', highlighted that 35% of people with diabetes experienced poor mental health during the pandemic, with a third feeling they did not have sufficient access to emotional and psychological support². The MS Society Cymru have recently noted that 81% of those interviewed with MS reported a decline in their mental health since the condition became a factor in their lives³.

Long-term mental health conditions are defined as disabilities under the Equality Act 2010, as long as they are deemed to have a "substantial, adverse, and long-term effect" on a person's ability to

https://www.ons.gov.uk/peoplepopulation and community/health and social care/disability/articles/disability by a gesex and deprivation england and wales/census 2021 #:~: text=In%20 Wales%2C%20 there%20 was %20a, in%202021%20 (Figure %206).

² https://www.diabetes.org.uk/about_us/news/diabetes-is-serious-ni-report

³ https://business.senedd.wales/documents/s123801/MHI%2049%20-%20MS%20Society%20Cymru.pdf

⁴ https://www.mind.org.uk/information-support/legal-rights/disability-discrimination/equality-act-2010/



carry out daily activities. Many of these conditions will be Severe and Enduring Mental Illnesses (SMI), such as schizophrenia or psychosis. However, it is important to note here that not every long-term mental health condition is an SMI, and not all SMI conditions are long-term.

The wider social context must be considered here. Wales has the highest poverty rate of the UK nations, with 34% of children living in poverty⁵. We know that people living in poverty and those living with a long-term physical condition have a higher risk of developing a mental health condition. Experiencing poverty; a lack of secure employment; inadequate quality or a lack of housing; facing racism and discrimination will all have a significant impact on our mental health. For people with long-term conditions, these factors will be felt more sharply.

In anticipation of the upcoming replacement mental health strategy, this inquiry can provide a valuable insight that can improve the lives of people with mental health problems across Wales. We hope to see the findings of other recent work undertaken by the Senedd and the Welsh Government influence the new strategy. We want to see those with lived experience listened to throughout, with their voices enabling effective co-production that shapes the document around the needs of the people of Wales. We believe this inquiry can play its part in this work.

1. Access to the right healthcare

Demand for primary mental health services is high, whether you live with a long-term condition or not. We know that around 30% of people who visit their GP have a mental health component to their illness⁶, and this will likely include people with long-term physical conditions.

This demand has affected two particular aspects of care: increased waiting times and a lack of immediate help post-diagnosis.

Waiting Times

We know that waiting times are currently high across the NHS. Treatment for both physical and mental conditions is often slow and delayed.

This is noticeable in the waiting times for high intensity or specialist psychological therapies, which are designed for people with SMI. These services are usually delivered in secondary care after a primary care consultation, usually with a GP. They can be life-changing for those who need support.

⁵ https://endchildpoverty.org.uk/wp-content/uploads/2022/07/Local-child-poverty-indicators-report-2022 FINAL.pdf

https://www.rcgp.org.uk/representing-you/policy-areas/mental-health-in-primary-care



The final Together for Mental Health Delivery Plan, which covers 2019-2022, sets the target of: "Improving the access, quality and range of psychological for therapies children, working age and older adults" as one of six key priorities for the period.

Our recent report, 'Too long to wait'⁸, highlighted the need for a reduction in waiting times for these therapies. Through data received from all 7 health boards, we noted that:

- In each month from April 2019 August 2020, thousands of people across Wales were waiting longer than the 26 week target to access psychological therapy, with hundreds of people waiting more than a year.
- The target for 80% of people to be seen within the 26 week target was not met in any of the 17 months to August 2020.
- There is significant variation across Health Boards on the numbers of people waiting for psychological therapies per head.
- Coronavirus has had a significant impact on access to psychological therapy and has
 exacerbated pre-existing issues, with less people accepted onto waiting lists and more
 people waiting longer for support.

For people with long-term physical conditions, these increased waiting times can be disruptive for their physical treatment. If they are also forced to wait for mental health support, their needs are likely to feel unmet.

In finding adequate solutions to reducing waiting times, it is important that video consultations are not treated as the only suitable option. During the pandemic, more primary care health services were delivered through these means. This method might suit some people. We know that Wales has proportionally more people living in rural communities⁹ than the rest of the UK, meaning places such as Powys or Ceredigion will likely face increased challenges to physically access healthcare. However, 13% of households in Wales lack any access to the internet. These people will require in-person care¹⁰.

Digital Health in Wales published an analysis of video consultations in January 2021, which suggested there is a "large appetite", suggesting a more blended model of in-person and online

⁷ https://www.gov.wales/sites/default/files/publications/2020-01/together-for-mental-health-delivery-plan-2019-to-2022.pdf

⁸ https://www.mind.org.uk/media/7181/too_long_to_wait.pdf

 $^{^{9}}$ https://www.gov.wales/sites/default/files/statistics-and-research/2018-12/080515-statistical-focus-rural-wales-08-en.pdf

¹⁰ https://research.senedd.wales/research-articles/coronavirus-poverty/



appointments is preferrable¹¹. We agree with this view. Nobody should be limited by access due to where they live or their access to the internet.

Recommendation 1: The Welsh Government should improve access to specialist psychological therapies for people with SMI in line with their needs.

Supporting physical health

According to NICE Guidelines "depression is approximately two to three times more common in patients with a chronic physical health problem than in people who have good physical health and occurs in about 20% of people with a chronic physical health problem."¹²

With regard to diabetes, for example, one recent study showed people with diabetes are twice as likely as the general population to develop depression or anxiety¹³.

For many people living with a long-term physical condition, it is not the standard procedure for mental health support to be provided at the point of diagnosis. This is important as being diagnosed with a long term physical health condition can change the way in which someone perceives themselves. They may be unable to undertake activities that previously helped managed their mental health. All this can have a destabilising impact as people realise their life is likely to change.

Of those interviewed by the MS Society, for example, 78% of respondents did not receive any mental health support when they were diagnosed¹⁴. Unfortunately, it is a similar story for adults across Wales living with all chronic, long-term conditions. Through our work with Diabetes UK Cymru, we identified that most health boards do not offer any access to condition-specific psychological therapies for those over 18 years old.

For diabetes, there is huge variance in access to condition-specific psychological therapies. There is no diabetes-specific access to psychological therapies for people outside of paediatric and transitionage care.

The first-hand experience of the clinicians we worked with indicated that, generally across Wales, access to psychological therapies and specialised mental health support for people living with long-term conditions is poor. As part of our research into the experiences of people living with diabetes,

¹¹ https://www.gov.wales/written-statement-250000-nhs-video-consultations-undertaken-wales

¹² https://www.nice.org.uk/nicemedia/live/12327/45909/45909.pdf

¹³ https://www.diabetes.org.uk/guide-to-diabetes/emotions/depression

 $^{^{14}\} https://mstrust.org.uk/news/people-ms-aren\%E2\%80\%99t-getting-enough-mental-health-support-survey-shows\#:$^:\text=The\%20survey\%20of\%20nearly\%203\%2C000, support\%20when\%20they\%20were\%20diagnosed$



we spoke to local health boards. These discussions indicated that appropriate interventions recommended under NICE guidelines are not being made, and that too often those in need of support are redirected back to primary care in order to access generic mental health support through Local Primary Mental Health Support Services (LPMHSS) or similar services.

We found that there is no pathway, model or strategy in Wales which supports access to psychological therapies for adults with physical health conditions. The most recent Diabetes Delivery Plan 2016-2020¹⁵ suggested that up to 41% of people living with diabetes in Wales experience poor mental health. However, the plan made neither any recommendations nor include any key service actions to health boards around mental health.

Recommendation 2: The Welsh Government should identify the support needs of people with long term physical health conditions and improve access to mental health support after a diagnosis.

Inpatient care

For those experiencing SMI, sometimes admission to an inpatient facility is the best option to provide adequate mental health support. This can be informal, which equates to around 72% according to the most recent data, or formal, which equates to 28%¹⁶. Formal detention usually occurs under the Mental Health Act, with 1933 people in Wales detained under Section 136 in 2022¹⁷.

There is evidence of wider issues in inpatient care that extend beyond the scope of this inquiry but are pertinent to fully supporting those with SMI. Key issues that require wider discussion in light of the upcoming replacement mental health strategy include:

- Improvements to the inpatient estate, as highlighted by HIW¹⁸.
- Analysing the use of restrictive practice and its potential for retraumatisation for individuals it is used on.
- A greater focus on person-centred and trauma-aware care.
- The workforce is an issue in and beyond inpatient care. A limited number of permanent staff can affect continuity of care and affect staff training on key issues such as restraint.

¹⁵ https://www.gov.wales/sites/default/files/publications/2018-12/diabetes-delivery-plan-2016-to-2020.pdf

¹⁶ https://www.gov.wales/sites/default/files/pdf-versions/2022/10/3/1664958616/admission-patients-mental-health-facilities-april-2020-march-2021.pdf

¹⁷ https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Mental-Health/Detentions-under-Section-135-and-136-Mental-Health-Act/section135136detentions-by-lhb-age-gender-quarter

¹⁸ https://www.hiw.org.uk/sites/default/files/2021-11/20211110MentalHealthAnnualReport2020-21EN.pdf



- Improving the quality of care and treatment planning.
- Improving the management of patient medications. HIW have reported examples of it being stored inadequately in a way that poses risks to patients.
- Communication between services and the patient's family/carers.
- Data collection should be improved, as mentioned below.

Recommendation 3: The Welsh Government should outline what action is being taken as a result of HIW's annual reports in order to improve patient experience.

Recommendation 4: The development of the inpatient workforce should be a priority, such as improving staff training and data collection.

2. Physical health checks for those with SMI

1 in 50 people in Wales live with a severe mental illness like schizophrenia or bipolar disorder¹⁹. People with SMI at greater risk of poor physical health and die 15-20 years earlier than the general population²⁰. 2 in 3 of these deaths are from preventable physical illnesses. Women with schizoaffective disorder can die as much as 17.5 years earlier.

Noting that there has been an increase of the share of people experiencing SMI from 11.7% prepandemic to 28.1% by April 2020²¹, the potential benefits of routine physical health checks cannot be overstated. This is recommended in the recent Health and Social Care Committee report on mental health inequalities and was accepted by the Welsh Government. The work outlined in the response to the report is encouraging. We hope to see the work commissioned and the project being undertaken in partnership between the National Collaborative Commissioning Unit and Royal College of Psychiatrists be both supported and integrated into the upcoming development of the replacement mental health strategy.

A fundamental part of this support will be in improvements to the quality of care and treatment planning. The most recent HIW report monitoring mental health hospitals highlighted that while there were some good pockets of good practice, many "lacked detail, did not adequately address identified risks, and did not include clear objectives and outcomes to support recovery²²." It is

¹⁹ https://www.gov.wales/sites/default/files/publications/2019-04/together-for-mental-health-summary.pdf

²⁰ https://www.england.nhs.uk/blog/achieving-more-for-people-with-severe-mental-

illness/#: ``: text = The %20 shocking %20 figures %20 are %20 that, conditions %20 such %20 as %20 cardiovas cular %20 discussions with the first of the first

²¹ https://www.cardiff.ac.uk/news/view/2534728-share-of-people-in-wales-experiencing-severe-mental-health-issues-more-than-doubled-during-pandemic,-report-finds

²² https://www.hiw.org.uk/sites/default/files/2021-11/20211110MentalHealthAnnualReport2020-21EN.pdf



encouraging that this is recognised in the Welsh Government's response to the mental health inequalities inquiry, but it must remain high on the agenda.

Recommendation 5: Physical health checks for people living with SMI must be offered routinely.

3. Equitable Access

Every person in Wales deserves equitable access to mental health services. However, we know that this is not case for certain groups. More needs to be done in particular for people from racialised communities and those living in poverty to ensure they feel services they use are 'for them'. This will require a trauma-informed, person-centred approach that listens to service users and adapts in a responsive way. These barriers will occur in both physical health and mental health services and working with communities to understand them and dismantle barriers should be at the forefront of all activity.

Stigma:

Challenging stigma is important when discussing long-term conditions. It can prevent people from seeking help as early as they should, which can affect future outcomes and lead them to require further, more intensive interventions at a later date. Through tackling stigma we can help create a culture whereby all communities feel it is ok to talk about mental health and which actively encourages people to seek help and support when suitable.

During the pandemic Time to Change Wales reported an increase in people experiencing self-stigma. This is where we seek to minimise our mental health as we believe there are bigger issues we or others are facing. This leads to neglecting the signs that we need support, even if it is just to talk to someone about our feelings and emotions. For people with long-term conditions, this could be in the form of thinking that they are a lower priority than an immediate health crisis, considering their conditions are likely to be lifelong.

This reflects the experiences of several local Minds in Wales who work in and with communities that experience high levels of deprivation. Their reflections include the need to encourage a conversation about mental health and have safe spaces for people to speak about their experiences. This would help to tackle the level of exclusion that communities feel and experience, whether financial, social or digital.



There is still a great degree of stigma around SMI, where most people's immediate awareness of conditions such as psychosis is sourced from negatively exaggerated portrayals seen in culture. Effectively tackling stigma will require strong leadership and progress through smaller impacts, which will have an impact on lives across Wales.

4. Together for Mental Health

The timing of this inquiry to fall during the development of the replacement 10-year mental health strategy offers a rare opportunity to embed solutions to some (or all) of the issues covered in the committee's work.

Much has changed in the ten years since the initial strategy was introduced, and recent work such as this inquiry; the Health and Social Care Committee's mental health inequalities inquiry; the HEIW workforce strategy; and the recent ORS review of Together for Mental Health should all influence a document that will likely be very different from the previous form, meeting the changing needs of a changing Wales.

Many experiences of poor mental health are short-term, triggered by a change in situation, such as difficulties with finances. However, for people living with a long-term physical condition, it is likely that this short-term experience will be more prolonged. But this does not need to be the case. A new strategy that can emphasise early intervention through clear service pathways can tackle this challenge.

SMI in particular must remain on the agenda for the future strategy. As a long-term condition affected by persistent stigma, it has clear physical ramifications that have historically been overlooked.

The lived experience of those living with such long-term conditions is fundamental for the effective co-production of a strategy that reflects the needs of the people of Wales. These people are more than the data, as everyone's experiences will be different. Clear principles and strong leadership and governance will benefit this no end.

Recommendation 6: The Welsh Government should take forward the findings of this inquiry for the new 10-year mental health strategy.

5. Rebuilding Minds after Stroke



The Stroke Association and Mind Cymru have recently begun a new partnership: Rebuilding Minds after Stroke. Around 7,400 people have a stroke each year in Wales and there are currently over 70,000 survivors living here.

The link between mental health and strokes is well documented. For example, in 2018, the Stroke Association surveyed people's experiences of mental health following their stroke²³, and found that:

- 52% experienced depression/ low mood.
- 47% experienced anxiety.
- 43% reported mood swings.
- 16% had experienced panic attacks.
- 12% had suicidal thoughts.

In Wales, there is little statutory stroke-specific emotional and psychological support on offer. The Stroke Association note that non-stroke specific statutory services can lack sensitivity to the specific impacts of stroke, such as on cognition and communication.

The new partnership will aim to plug the main gap in level 2 support, designed for those who are struggling emotionally after a stroke and may be experiencing mild to moderate depression and/ or anxiety. This work will help support people across Wales who need stroke-specific help. The committee should note this work and any potential future benefits that such a scheme might bring to the mental health of those with long-term physical health conditions.

6. Self-Help

Mind offers a range of self-help tools that could benefit people living with a long-term condition. Principal amongst them is <u>our website</u>, which hosts an archive of resources on mental health conditions and guides to support around common issues, such as seeking help in primary care or guidance with the cost of living crisis.

Our <u>helplines</u> also offer support. Our Infoline provides information and a signposting service. Our Legal Line offers legal information and general advice on mental health related law in England and Wales.

We have a <u>network of Local Minds</u>, which has provided mental health services across England and Wales to at least 396,000 people²⁴. Each is unique and includes tailored services to the community they represent, such as talking therapies and peer support.

²³ https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-1-hidden-effects-of-stroke

²⁴ https://www.mind.org.uk/about-us/local-minds/



Our <u>Supported Self-Help programme</u> (formerly known as Active Monitoring) is a 6-week guided self-help intervention. It is aimed at people with mild-to-moderate symptoms of mental health problems. Clients can self-refer, and there are seven pathways they can access depending on the needs they present with.

Supported Self-Help meets an unmet need in mental health service provision. It provides clients with access to support in a short timeframe, where the option otherwise would be waiting on lengthy NHS waiting lists for support (often months) or not accessing support at all.

The service prepares people to look after their mental health beyond engaging with the service. It empowers people to support themselves and equips them with tools and techniques to do so.

7. Recommendations:

- **1.** The Welsh Government should improve access to specialist psychological therapies for people with SMI in line with their needs.
- **2.** The Welsh Government should identify the support needs of people with long term physical health conditions and improve access to mental health support after a diagnosis.
- **3.** The Welsh Government should outline what action is being taken as a result of HIW's annual reports in order to improve patient experience.
- **4.** The development of the inpatient workforce should be a priority, such as improving staff training and data collection.
- 5. Physical health checks for people living with SMI must be offered routinely.
- **6.** The Welsh Government should take forward the findings of this inquiry for the new 10-year mental health strategy.