Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar anghydraddoldebau iechyd meddwl

This response was submitted to the Health and Social Care Committee consultation on mental health inequalities

MHI 37

Ymateb gan: | Response from: Fair Treatment for the Women of Wales

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Senedd Health and Social Care Committee Inquiry:

Mental Health Inequalities

Name of organisation: FTWW: Fair Treatment for the Women of

Wales

1. FTWW is the only patient-led women's health equality charity in Wales, supporting and advocating for women and people assigned female at birth* who are disabled and / or living with long-term health conditions. We campaign for better women's health services and equitable access to them, particularly as many of the health issues which predominantly affect females have suffered historical lack of investment and prioritisation in Wales and beyond. Mental health is no exception, with the specialist services our beneficiaries need difficult to access and more local, 'lower level' support often unavailable.
*Hereafter, reference will be to 'women' but, for the purpose of this document, should be considered inclusive of girls and people assigned female at birth.

2. As described in previous submissions to the Committee, the pandemic has undoubtedly had a hugely significant and detrimental impact on waiting lists for care, including mental health services. However, it has also shone a light on pre-existing problems in Wales. These include:

- a lack of specialised services and personnel
- an absence of pathways to access specialised services elsewhere
- an ongoing failure to fully appreciate women's specific needs, both when it comes to physical and mental health

- a severely over-stretched mental health workforce
- a worrying tendency to assume that 'silent' patients are 'managing' patients

3. As the pandemic and related periods of self-isolation continue, the latter is particularly concerning. With increasing numbers of 'new' patients experiencing mental health concerns over this period and seeking support, pre-existing patients, a significant proportion of whom are living with moderate to severe mental health issues, have found themselves without access to services. Limited capacity and consequent reduced communication with these patients can result in marked deterioration, compounded by some patients' reluctance to seek help during the pandemic due to escalating anxiety: a lack of contact should not be assumed to mean that patients are 'coping'.

4. FTWW's research continues to show that those health conditions which disproportionately impact women are often associated with a lack of access to specialist services, with mental health no exception. There continues to be a lack of investment in measures to record data on either prevalence or patient-reported experiences and outcomes, which then leads to a lack of appropriate services or pathways.

5. Issues like self-harm, eating disorders, obsessive compulsive disorders and body dysmorphia, premenstrual dysphoric disorder (PMDD), severe peri-natal mental health problems, and trauma all have a significant impact on women, and access to specialist / in-patient care is limited, with few discernible pathways to care out of area. This has a considerable knock-on effect on local care-providers, with patients experiencing a revolving door of waiting for less specialised care which may only provide short-term or inadequate support, adding to ever-increasing local waiting lists and worsening prognoses.

6. Self-harm: the taboo nature of this issue is highly problematic, not least because it deters sufferers from seeking help but also because it makes it difficult to establish numbers affected and identify solutions. Nevertheless, most reliable data for self-harm available in Wales is derived from hospital admission data, with approximately 5,500 admissions in Wales each year (https://gov.wales/sites/default/files/publications/2019-08/talk-to-me-2-suicide-and-self-harm-prevention-strategy-for-wales-2015-2020.pdf). Self-harm can affect people of all ages and genders, but we know it is more common in females across all age groups and that numbers are reported to be rising. This indicates an urgent need to develop and implement person-centred interventions.

7. Eating disorders: according to Beat's latest estimation, nearly 58,800 people in Wales have an eating disorder (https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics/), ranging from anorexia nervosa, bulimia nervosa, binge-eating

disorder, and others; they are considered serious mental illnesses, with anorexia having the highest mortality rate of any mental illness. They affect people of any age, gender, ethnicity, or background. However, around 75% of those affected are female. Delayed diagnosis and access to appropriate support is a significant problem, with a postcode lottery for care and no specialist inpatient facilities in Wales for those with serious manifestations.

8. Obsessive Compulsive Disorder and Body Dysmorphia: OCD and BDD are serious mental health conditions that can severely impact people's lives and wellbeing. More common in women and girls, these conditions may be seen alongside eating disorders, anxiety, and depression (https://www.womenshealth.gov/mental-health/mental-health-conditions). In Wales, depending on staff available, there is some provision in secondary care settings, with patients offered medication and / or a limited course of psychological therapies. However, if those interventions are not sufficient or successful, or the patient's case particularly severe and / or long-standing, therapy will not be provided indefinitely, nor is there the option to refer to tertiary-level specialist / inpatient services elsewhere.

9. Perinatal mental health: around 1 in 5 women will be affected by mental health problems during pregnancy and/or up to a year after giving birth, although these issues can become chronic and long-term in nature if not adequately addressed in that period. Having a pre-existing or previous mental health problem can be a risk factor for perinatal mental health problems, making early identification and support for those people essential. Numbers affected are thought to have risen during the pandemic (https://ncphwr.org.uk/wp-content/uploads/2020/09/Born-In-Wales-Newsletter-Sep2020-1.pdf), both as a consequence of growing health anxiety and reduced access to familial support at home and during antenatal visits. At the same time, FTWW is hearing from patients that access to perinatal support may have been delayed due to fewer in-person appointments with health visitors. There remains only one specialist in-patient facility for severely affected mothers and their babies to stay together, a 6-bed unit in Swansea. Whilst options are being explored by Betsi Cadwaladr UHB to provide access to beds in a neighbouring Trust in England, this poses additional challenges for those whose first language is Welsh.

10. Trauma: experiencing stressful, frightening, or distressing events can have a long-term impact on someone's mental health and wellbeing. Some conditions are also known to develop as a direct result of trauma, including post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (complex PTSD). Complex PTSD can occur when someone has experienced multiple and persistent traumas, intersectional inequalities, and oppression, such as ableism, racism, and gender-based violence. We know that In England, young women aged 16-24 have higher levels of PTSD than any other group

(https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/765821/The_Womens_Mental_Health_Taskforce_-_final_report1.pdf). As a charity supporting disabled women, FTWW is very much aware of the various stressors experienced by our community, including birth and medical trauma. Current service provision is often not designed with women's specific needs and vulnerabilities in mind, which can further exacerbate trauma.

11. Another area where women are more likely to experience inequitable care and poor outcomes is in neurodivergence, including autism and attention deficit hyperactivity disorder (ADHD). Unhelpful gender biases and stereotypes about what constitutes 'typical' presentation sees many neurodivergent women dismissed, resulting in diagnostic delays, delayed / ineffective support, and poorer health outcomes. Evidence suggests that autistic women are at increased risk of loneliness and social isolation, and of dying by suicide, than their male counterparts (https://link.springer.com/article/10.1007/s10803-016-2872-8).

12. More generally, FTWW's members report various problems in their experiences of healthcare and services: for those with a pre-existing diagnosis of a mental health condition or neurodivergence, it can lead to assumptions that their physical symptoms are attributable to that, making effective dialogue and shared decision-making difficult to achieve. The inherent danger in this is that those patients affected become reluctant to engage with services at all, resulting in poorer prognoses and increased risk to health.

13. As well as experiencing prejudices based on 'formal' diagnoses of mental health conditions, FTWW members often recall incidences where physical symptoms and conditions have been erroneously attributed to a non-existent mental health issue. Many attribute this situation to historical prejudices and stereotypes, where women's pain is underplayed or dismissed as being a result of the 'female psyche' and a tendency to be more depressed, anxious, and 'hysterical'. Ironically, members report that experiencing prejudices of this nature can, in fact, *cause* them to experience anxiety and depression but that they have rarely, if ever, been referred to mental health services on these occasions, despite some feeling that this kind of support may well help them to cope with the effects of chronic and acute pain, for example.

14. There are other occasions where our members tell us they would particularly appreciate mental health support. These include pregnancy loss and infertility, both of which can result in anxiety, depression, and the distress associated with bereavement or loss. Neither of these issues have been sufficiently addressed to date by the Welsh Government, with lack of investment in ensuring universal and timely care pathways to appropriate psychological support are in place.

15. All of the above information is based on our ongoing conversations with our online community forum. As part of our response to this consultation, we have additionally sought our beneficiaries' thoughts via a survey and focus group. The questions asked to guide discussion were:

- ***What are the factors that are contributing to your poor mental health?***

- ***What are some of the key issues you have faced in accessing Mental Health support and how effectively can existing services meet your needs?***

- ***How could your experience of using mental health services be improved?***

16. Our members told us that factors contributing to their poor mental health include:

- Language used by healthcare professionals during labour, i.e., 'failure to progress', and, 'failure to produce milk', which compounded perinatal mental health issues and led to PTSD

- Repeatedly not being believed in healthcare settings and having to repeatedly explain symptoms and / or justify help-seeking

- The ongoing struggle to access specialist healthcare outside of one's own health board, requiring the skills and persistence to self-advocate for better care when resilience is low, and 'feeling like a pest' for trying

- Lack of mental health support available to those with chronic physical health conditions

- Increased stress and anxiety at not meeting the criteria for the Community Mental Health Team's intervention, even when counselling services offered via the GP have not been adequate

- Referrals to occupational therapy rejected, making continuing in employment more challenging

- Being denied voice, choice, and control in healthcare decision-making

- Trying to access disability benefits, such as PIP (Personal Independence Payment), a process which was described by one respondent as being,

'degrading and dehumanising and has had a really detrimental impact on my mental health'

- Widespread ableism, with disabled people feeling like they are 'judged' and 'at fault'. Many describe having lost friends and relationships because of their impairments and consequent lack of understanding, resulting in increased isolation, loneliness, and worsening mental health. For those who are termed, 'clinically extremely vulnerable', the impact of shielding for extended periods during the pandemic has compounded both isolation and anxiety

- The stress of trying to juggle the responsibilities of work and home whilst living with ill health and not being able to access care in a timely fashion has had a significant impact on mental health and wellbeing.

17. Our members described some of the key issues faced in accessing Mental Health support as follows:

- Unacceptably long waiting lists for psychological therapies such as Exposure & Response Therapy and Eye Movement Desensitisation and Reprocessing (EMDR) alongside a propensity to medicate rather than deal with underlying issues

- Lack of joined-up approaches between specialties in physical and mental health services and a lack of training or pathways for hormone-mediated mental health conditions, such as Premenstrual Dysphoric Disorder (PMDD)

- An over-stretched NHS workforce and lack of capacity results in many patients being offered online CBT courses which are not adequate for their needs and can exacerbate underlying feelings of loneliness and isolation, something which disabled / chronically ill people are at an already increased risk of experiencing

- Feeling like going private is the only way to access appropriate therapy in a reasonable time-frame and for it to be effective

- A widespread lack of appreciation for how mental health can be negatively impacted by physical health conditions, with recommendations of exercise / yoga not always appropriate for people's physical capabilities

- A need for improved awareness of neurodivergence in females, with sufficient investment in training and provision of appropriate support in all healthcare

settings, including diagnostic assessments and a wider understanding of the overlap between neurodivergence and physical and mental health issues

- The need to ensure a joined-up approach between Integrated Autism Services and Mental Health Services, particularly with regards to information-sharing

- Access to Crisis Teams can be very problematic due to capacity issues, with telephone lines frequently busy and messages not always communicated. Crisis Teams would also benefit from additional awareness training on the disparate ways in which women and other people with protected characteristics might present when in a mental health crisis.

18. Our members told us that improvements to mental health services in Wales should include:

- More services available in the Welsh language and British Sign Language because not being able to communicate effectively at times of distress can compound poor mental health

- Making information on service provision widely and easily accessible, with signposting at every level / opportunity

- Increased training for existing and future healthcare professionals to identify and manage situations which can have a pronounced mental health impact on women and girls, such as menstrual health and wellbeing, gynaecological procedures, pregnancy and pregnancy / baby loss, infertility, childbirth, and menopause

- Increased recognition and support for those experiencing mental health problems related to long-term physical illness and pain, ensuring that psychological support and wellbeing interventions are offered to patients as part of a comprehensive and holistic management programme, not as a panacea or alternative to physical treatment

- Increased awareness and outreach support for people who have difficulties leaving the family home for support or who may not always reach out to services for assistance, including disabled and housebound people, people experiencing domestic violence, unpaid carers

- Increased awareness and investment in appropriate support services for those experiencing socio-economic challenges which can impact on their mental and physical health, including people in poverty, and homeless people

- Development of one-stop 'shops' or clinics for those with physical and mental health co-morbidities

- Enable people to self-refer into the mental health services and therapies they feel best suit their needs, rather than requiring long waits for 'gate-keeping' appointments

- Avoid drastic cut-off points when transitioning from CAMHS to adult mental health services: patients would experience better outcomes if the way in which mental health services are delivered changes to a model where professionals cover all age groups and become the named case-worker for fewer individuals throughout their lives / whilst they need services

- Undertake research into the psychological impact shielding has had on people during and beyond the pandemic

- A commitment from all in public services and public life to have disability awareness training, learn the social model, adopt and implement it

- Ensure that all health services are co-produced, from inception through to delivery and evaluation so that they are more fit for purpose

- Make careers in mental health more attractive, perhaps by using paid training packages which require recipients to work locally in that service for a defined period of time

- Devolve social security / benefits to the Welsh Government with the aim of supporting and empowering disabled people so that they thrive and therefore require fewer costly interventions from mental health services, are more likely to be able to continue to lead productive lives, and are less likely to be in poverty.

19. In its consultation on the mental health workforce, Health Education and Improvement Wales discusses a 'volunteer workforce' as an important part of workforce planning in mental health services. Some of our respondents expressed concerned at this approach as, often, volunteers with an interest in contributing to mental health support and activities are doing so because they have lived, possibly ongoing, experience of mental

health issues themselves. More than one of our respondents described inadvertent pressure put on them to 'lead' groups which they were originally attending to help them manage their own needs, which ultimately led to an exacerbation / relapse of their mental health issues. Volunteers should not and cannot be considered a solution to gaps in the paid workforce, not least because they do not have the same rights or responsibilities under employment law; nor should they be seen as an alternative to formal mental health services / support even if they can and do offer a valuable adjunct to it.

20. Despite the above note of caution, many of our respondents found third sector / peer support to be invaluable in terms of reducing isolation and improving wellbeing. However, there were concerns that this kind of provision is not adequately resourced, which undermines the value placed on it by both service-users and public service providers. Lack of sustainability is a huge concern to both third sector organisations and their beneficiaries. Variation in third sector / grassroots / peer-led provision across Wales is also problematic.