

AEC 50

Ymateb gan: Triniaeth Deg i Fenywod Cymru

Response from: Fair Treatment for Women of Wales

FTWW Response to Senedd Children, Young People, and Education Committee Inquiry:

Do disabled children and young people have equal access to education and childcare?

Fair Treatment for the Women of Wales (FTWW) is a pan-Wales patient-led charity and disabled people's organisation (DPO) focused on female health equality.

As an organisation advocating for women, girls, and people assigned female at birth who are disabled and / or living with long-term and recurrent health issues we offer support to a growing number of beneficiaries who are struggling with

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- 1) The extent to which children and learners are currently able to access all parts of childcare and education provision, including the way in which the curriculum is taught and extra-curricular activities.**

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1) The extent to which children and learners are currently able to access all parts of childcare and education provision, including the way in which the curriculum is taught and extra-curricular activities.

As an organisation advocating for women, girls, and people assigned female at birth who are disabled and / or living with long-term and recurrent health issues we offer support to a growing number of beneficiaries who are struggling with menstrual health conditions like endometriosis, Polycystic Ovary Syndrome (PCOS), and Premenstrual Dysphoric Disorder (PMDD), the symptoms of which often start in school. Unfortunately, when – as is commonplace – these conditions are not diagnosed promptly or optimally managed, they can ultimately result in long-term impairment and disability. Many of our members tell us that they wish they had been able to access appropriate support and signposting in school as this might have reduced years of unnecessary suffering.

On the back of our members' testimonies, FTWW was amongst those who called on the Welsh Government to make menstrual wellbeing education mandatory element of the secondary school curriculum for Wales. We are pleased that the topic now features in the Health and Wellbeing Area of Learning and Experience and 'What Matters' code and hope that this will result in its being covered consistently and well, improving the experiences and outcomes of 52% of the school population.

Whilst there remain challenges in ensuring that menstrual health is discussed openly and accurately in wider circles, including within families, formal education settings play a vital role in disseminating information and tackling stigma. It is important therefore that this offer is accessible to as many young people as possible, with school environments actively supportive spaces for those with additional impairments and / or who are neurodivergent.

As mentioned, menstrual health conditions can be long-term and have a significant impact on students' ability to carry out daily activities. We need to be

confident that, as far as possible, the content and delivery of menstrual health education is of a consistently high standard across Wales to avoid inequity, and to help expedite diagnosis and help-seeking. Our understanding is that Welsh Government's Period Proud Wales Action Plan aims to develop resources to support with this but, right now, we are unsure as to how far menstrual wellbeing education is being embedded in schools and its accessibility.

Historically and still today, menstruation and associated health conditions have been shrouded in taboos, myths, and misinformation so it is vitally important that work is undertaken to equip teaching staff and associated personnel with the confidence and knowledge to lead on this subject area. They must have access to evidence-based resources and / or specialists who can deliver accurate information in a way that empowers learners. Equally, however, all school personnel should be trained to a standard where they can comfortably handle menstruation-related enquiries and signpost appropriately.

2) The extent to which children and young people have been excluded from aspects of education or childcare due to their disability or neurodivergence.

It is worth noting that a considerable number of students (and staff) will be living with 'invisible' symptoms or illness and are being disabled by societal attitudes and systems, including in educational settings. Aside from disability related to menstrual health and associated conditions, we are also concerned that educational settings can sometimes be physically inaccessible to those with mobility-related impairments, and that the typical school / classroom environment, physical education, and extra-curricular activities can sometimes be exclusionary. Often, school architecture and furniture can create challenges for those with physical impairments, whilst large class sizes and the way classrooms are set up can pose difficulties for those who struggle with their mental health. Frequently, it seems that the solution is to segregate disabled learners from their peers, but this can only serve to exacerbate perceptions of 'difference' and perpetuate both internalised and societal ableism.

Physical Education (PE) and related extra-curricular activities often don't cater to needs outside of the default 'able-bodied' person, which can have implications for

health and wellbeing far into the future. We hear from many disabled women whose experiences of PE were poor, with them often ending up sitting alone in a classroom whilst others participated in team sports outside. They tell us that this experience left them reluctant to engage in physical activity later in life with consequent implications for their longer-term health. Clearly, there needs to be a proactive approach to diversifying what's on offer in schools for disabled learners so that they get the opportunity to engage in activities that 'work' for them and feel confident about participation beyond school.

Fundamentally, disabled students (and / or their families or advocates) should be enabled to say when activities and spaces don't meet their needs or are exclusionary. They should be confident that schools and local authorities will commit to addressing barriers in a timely fashion and without making them feel like they – and their impairments – are the 'problem'. This is very much in line with the Social Model of Disability, an approach to which the Welsh Government is committed.

The Social Model recognises that what 'dis-ables' people with impairments and long-term health conditions is external to them, such as systems, processes, environments, and attitudes, rather than a person's impairments or cognitive differences. We would therefore urge the Committee, policy-makers, local authorities, and educational settings to use social model language and abide by its principles wherever possible.

As mentioned, FTWW responded to the Welsh Government's recent consultation on draft guidance around school attendance, 'Belonging, Engaging, Participating'. The guidance noted that 'Certain protected characteristics are associated with learners having a greater risk of absence from school and exacerbate the challenges they already face. Promoting good attendance is therefore particularly important in these cases'. We would echo our response to that consultation here, in that, where disabled students are concerned, 'promoting' should be replaced with 'enabling and supporting'.

It is crucial that education providers engage with, understand, and co-produce solutions to the challenges disabled learners face, removing barriers so that they can participate in an equitable way. It is particularly important not to make assumptions about disabled people's unique and often intersectional experiences

and needs: every school or educational establishment and local authority should have protocols in place which facilitate engagement and learning of this nature.

The Education Welfare Service is seen as providing support to ensure attendance and address problems relating to absence, which may well relate to students' physical health, mental health, and impairments. It is vital therefore that the EWS is similarly equipped to understand and utilise the social model of disability so that they can advocate for disabled learners and direct positive action in terms of making educational settings accessible and supportive environments.

3) The extent to which families and children feel that they have been affected by direct, indirect or discrimination arising from disability.

We are concerned that there is often a tendency not to look at challenges and barriers through an intersectional lens. Health issues which predominantly impact females (such as those linked to menstruation, gynaecology, chronic pain, chronic fatigue, eating disorders, and self-harm) are often not taken seriously or are 'normalised', which disadvantages females throughout the life-course.

In the UK, girls and women who are Black or of an ethnic minority background, are disabled, and have experience of socio-economic deprivation are even more likely to encounter difficulties in seeking and accessing support, whilst those who are diagnosed as autistic or having ADHD encounter diagnostic over-shadowing, where symptoms of disparate health conditions are attributed to their neurodivergence. The result is delayed access to optimal treatment, trauma, and further disability. It is essential that education settings are organised in such a way that they become preventative and supportive spaces rather than further exacerbating trauma and entrenching disadvantage.

For some, onset of puberty and periods (usually experienced around the time of starting secondary school) can mark the start of long-term, sometimes progressive, health conditions like endometriosis, PCOS, and PMDD. All of these can have a significant impact on sufferers' education, prospects, and lives. Indeed, under the Equality Act 2010, those living with these conditions would likely be considered 'disabled'. In the workplace, they would be entitled to consideration of

reasonable adjustments but, in educational settings, there isn't the same sort of protection.

As mentioned, we are concerned that there is insufficient training for staff to identify, support, and appropriately signpost pupils living with the escalating impact of symptoms such as severe menstrual pain, heavy bleeding, and hormone-mediated mental health problems. The result is that many struggle in silence, will sometimes be penalised for not performing satisfactorily, or will miss school altogether.

Currently in Wales, there is no consistent process to calculate menstrual-health-related absenteeism or presenteeism (where pupils will attend school but do not achieve their potential due to their symptoms). This lack of data about prevalence and impact undoubtedly contributes to the barriers and discrimination experienced. Many women tell us that they and their children have found describing menstrual health issues and needs difficult due to historical taboos, whilst symptom reporting has been problematic due to negative gender stereotyping, unhelpful attitudes, and a widespread lack of knowledge. Many of them describe this as having a pronounced impact on their mental health.

We are therefore delighted that mental health and wellbeing is to feature prominently in the new secondary school curriculum for Wales. However, we would like to see much more emphasis placed on the link between menstrual wellbeing, menstrual health conditions, and mental health, including hormone-mediated mental health conditions.

Whilst more severe hormone-mediated psychiatric disorders may only affect a relatively small proportion of students, many more will be impacted by pre-menstrual syndrome, and even more will experience embarrassment, anxiety, and isolation that comes from experiencing painful and heavy periods without adequate recourse to support, facilities, and products. The Welsh Government's Period Dignity Strategy has the potential to make a significant and positive difference to the experience of learners but we would like to see concrete evidence of these strategic aims being fulfilled in a meaningful way in all educational settings in Wales, with students' own testimonies key to learning.

As it stands, we are concerned that toilet policies in many schools are disabling

students with both continence and menstrual health-related issues. Learners are often required to produce a toilet pass (applied for in advance) or explain their reasons for needing the toilet in front of the class. Sometimes they will be denied access to the toilet. Clearly, this is neither in the spirit of the Welsh Government's Period Dignity Strategy, nor does it seem to be in line with human rights legislation that mandates people's right to access sanitation.

At the same time, we continue to hear from other organisations and individuals that not all schools are complying with the Welsh Government's calls for period products to be made freely available in the toilets. There are reports of products being kept in locked cupboards in offices which requires students having to leave cubicles whilst leaking to find the relevant staff member to unlock said cupboard. All of this inevitably results in more time away from the classroom, as well as personal embarrassment and impact on cleanliness / personal hygiene. We believe that period products should be as readily available as toilet paper.

We believe that reconsideration of toilet policies and compliance with the Welsh Government's 'period proud' principles would promote the welfare and dignity of all female students, particularly those severely affected by menstrual health issues and period poverty. It would also have positive benefits for those students living with continence issues who currently find themselves disadvantaged or excluded due to their impairments.

4) The impact of any lack of or limited access on a child or young person's mental health and well-being and educational outcomes.

Being unable to participate fully or equitably in education as a result of an impairment, learning disability, or neurodivergence can have a significant impact on learners' future prospects and more immediate wellbeing, with some students finding the environment so challenging and traumatising that they will avoid school completely.

The Welsh Government's 'Belonging, Engaging, Participating' draft guidance described the need for, 'support for emotionally based school avoidance (EBSA) – an umbrella term used for experience of those who have severe difficulty in attending school due to emotional factors (and) emotional distress experienced

around attending school'. Firstly, we would suggest that there needs to be certainty that these experiences don't derive from an underlying health issue or pathology which learners feel too embarrassed to discuss openly, i.e., menstruation and related pain and distress which can result in anxiety, depression, and, ultimately, school avoidance. Education providers also need to be sure that they have addressed any environmental barriers that make access more problematic for disabled and / or neurodivergent students.

Increasingly, we have noticed policy and guidance refer to 'resilience' as a personal attribute people need to develop to better cope with life's challenges, some of which might present in the form of emotionally based school avoidance. However, the concept of 'resilience' can sometimes mask systemic injustices and inequalities. In fact, personal resilience may well encompass a range of coping mechanisms that individuals have developed and honed over time in order to manage their circumstances. For some disabled and chronically unwell learners, coping strategies may include absenting themselves from schools if, for example, those settings don't offer the support, provisions, or reasonable adjustments that students need to attend comfortably, equitably, and without prejudice.

Guidance and personnel must be careful therefore not to patronise those who are disabled and disadvantaged by simply advising / 'training' them to be more 'resilient', or 'tough'. It is vital to avoid the sense that the individual is at fault rather their environment or circumstances. Where education is concerned, there must be investment in engagement with disabled students and their families, enabling clearer identification of systems and structures which can disadvantage and disable, and both a willingness and sufficient resource to address them. Ultimately, this should lead to the creation of spaces which are inclusive and supportive, tailored to people's individual needs. This includes continuing to make available the full range of creative subjects which we know benefit mental health.

5) Whether parents of disabled and neurodivergent children and the children themselves receive effective information and support from local authorities and schools

We are concerned that neurodivergent girls and their families are not able to access appropriate information and support in a timely way to enable their

participation in school and extra-curricular activities. Schools will often be key to identifying neurodivergent pupils and initiating the support packages they need. However, there remains an inequity when it comes to neurodivergent girls, with diagnostic models and interventions based on the 'typical' male model. This results in long diagnostic delays and a lack of appropriate support. Many neurodivergent females will experience misdiagnoses, often of mental health conditions / psychiatric disorders, resulting in inadequate care and deteriorating wellbeing. Of course, neurodivergence can exist alongside mental health issues so it is important that signposting and support encompasses these wide-ranging needs.

Evidence suggests that neurodivergent females will often 'mask' their struggles as a way of trying to conform with gendered expectations, such as being polite, hard-working, and organised, and to fit in with their peers. 'Masking' can lead to anxiety and depression, school avoidance, and forms of self-regulation and control manifesting as issues like Obsessive-Compulsive Disorder (OCD), eating disorders, self-harm, and emotional meltdowns outside of school. There is also evidence to suggest that autistic females are at higher risk of suicide. It is therefore of paramount importance that educational and healthcare settings are equipped to identify and offer support to those affected as quickly as possible, including working with individuals, their families, and advocates, to map out and accommodate learners' needs.

6) The extent to which there is adequate provision for children with different types of disabilities.

Core to FTWW's mission as a patient-led charity and disabled people's organisation is to see those with lived experience of disadvantage empowered and enabled to participate in the co-production of the services they need and use. A range of robust and accessible mechanisms need to be in place in all areas of policy and practice so that decision-makers and delivery partners can hear directly about the barriers disabled people face and what they need to participate equitably.

It is important not to make assumptions but to be open to learning about diverse and intersectional experiences and priorities and have the resources available to

accommodate those. This kind of approach, if embedded consistently and sustainably across Wales, would ensure adequate provision for young people with all manner of impairments and needs.

Above all, we would like to see Wales as a nation actively embrace the social model of disability so that those who are living with impairments and long-term health conditions, visible or not, are enabled to lead their best lives without experiencing prejudice and injustice.