

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 79

Ymateb gan: | Response from: Triniaeth Deg i Fenywod Cymru | Fair Treatment for the Women of Wales

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrsgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?

Q1. Which of the issues listed above do you think should be a priority, and why?

Of the Committee's pre-existing list of priorities, FTWW's members have highlighted

- public health & prevention
- access to mental health services
- access to services for long-term chronic conditions, including musculoskeletal conditions

as those priority areas most in line with their own.



In terms of public health and prevention, our members see this as vital in terms of women's* health, not least to address its glaring omission from Welsh Government's 'Healthier Wales' strategy.

FTWW's manifesto (1) highlights the important role public health awareness campaigns and literature can play in ensuring early intervention in women's health-related issues, preventing harm, and reducing long-term costs to services. This would include literature on menstrual wellbeing and associated conditions being widely and publicly available, normalising discourse on what is often considered a taboo subject, increasing awareness of symptoms that might be signs of a menstrual health condition, and enabling timely help-seeking.

Health conditions that would benefit from such an approach include heavy menstrual bleeding and fibroids, endometriosis, adenomyosis, poly-cystic ovarian syndrome (PCOS), pre-menstrual dysphoric disorder (PMDD), and menopause. A heightened role for Public Health Wales in improving women's health is vital, not least because of the costs incurred to the public purse of not pursuing a preventative approach; many of those affected do not complete their education or fulfil their career potential as a consequence of symptoms, delayed help-seeking, and ineffective treatment when they do. Equally, ONS data shows that women experience fewer 'disability-free' lives than men (2), more years living with the impact of chronic health conditions and are more likely to live in financial hardship as a result. It is clear that a public health and preventative approach is key to addressing these health inequalities. Public Health Wales should support and drive forward pan-Wales investment in services for menstrual health-related issues as the numbers affected make this area a major cost-burden to the Wales economy and a significant factor in decreased wellbeing for females, their families, and communities.

We would call upon the Committee to:

- recommend Public Health Wales make women's health, menstrual wellbeing, and associated health conditions a key part of their future planning, in line with the prevention and early intervention agenda
- ensure that both the Committee itself and public agencies within Wales work with organisations like FTWW to ensure co-production of strategy and resources.

**please note that when referring throughout this submission to women's health, we are including girls and those assigned female at birth (AFAB)*

With regards to access to mental health services, our members pointed out that 'access' cannot be facilitated if the services do not exist in the first place. Whilst there are, reportedly, pockets of good practice in Wales, it seems that there is little pan-Wales learning taking place, with inconsistent investment in recruitment, training, retention, specialisation, and pathways across – and beyond – Wales, resulting in a postcode lottery of the worst kind.

Our manifesto highlights the lack of specialist mental health services for issues predominantly affecting girls, women, and AFAB, including a significant shortage of in-patient beds for those experiencing severe peri-natal mental health conditions where they can stay with their baby and remain as close to family and local support networks as possible. We would also ask that the cut-off point for community peri-natal mental health services (currently 6-12 months post-birth) be extended to 2 years post-birth across Wales and that there is joined-up care provided should access to adult mental health services be required beyond that point.

We are also very much aware of the dearth of specialist provision for those who experience episodes of self-harm, eating disorders, and obsessive-compulsive disorder (OCD), issues which also tend to predominate in females. Currently, there are no in-patient clinics in Wales and no confirmed referral pathways into England for these patients. Meanwhile, provision of advanced skills personnel in out-patient settings is patchy or non-existent. In line with the prevention / early intervention agenda, it is vital that those affected by these issues are quickly and easily enabled to access tertiary-level services irrespective of location so that they are more likely to recover.

There are also significant issues around access to mental health support for neurodiverse people, including autistic individuals and those with ADHD. We would urge Welsh Government to invest in co-producing specialised services able to provide person-centred support for this community's particular needs, including additional training for existing mental health personnel.

Additionally, we would like to highlight that, despite Welsh Government's commitment to the recommendations made in its 2019 Gender Equality Review, there remains no dedicated recurrent miscarriage clinic/s in Wales, and an associated lack of specialist bereavement support and counselling for those affected. Given that this absence of support can result in post-traumatic stress disorder (PTSD) for a significant number, we would urge the Committee to hold Welsh Government to account over its failure to fund either the development of recurrent miscarriage clinics in north and south Wales or prioritise associated mental health service provision.

As an organisation representing those living with chronic illness across Wales, we would also like to see equitable provision of lower-level therapies and psychological interventions for those living with long-term physical health problems, as part of a multi-disciplinary package of care supporting a holistic approach to symptom management. As it stands, there is a real disconnect between mental and physical health, with many professionals not appreciating how both physical symptoms of disease (ie chronic pain) and lack of recognition / support from public and medical professionals alike can contribute to escalating anxiety, depression, and trauma. It is vital this is addressed, by developing – and co-producing - unconscious bias training in healthcare settings, implementing NICE-endorsed Shared Decision-Making protocols, and ensuring a joined-up approach to services, with the person (patient) at the centre.

We would call upon the Committee to:

- hold Welsh Government to account over its ongoing failure to ensure parity of esteem and funding for mental health and an apparent lack of oversight of health boards' activity in this regard. We are concerned that many commitments have

been made both to mental health and services for autistic adults which have subsequently not transpired, partially due to a lack of financial investment on the part of Welsh Government and partially due to a lack of action in ensuring that the health boards responsible for delivering services are equipped – even minded - to do so

- work collaboratively on developing and implementing innovative approaches to the recruitment, training, and retention of mental health professionals by offering contracts which pay for initial training and continuing professional development if personnel fill positions locally for a set amount of time
- challenge Welsh Government / health board protocols which prevent out of area referrals for specialist care and support in the development of mechanisms which are more patient-centred, empowering patients themselves to facilitate and / or co-produce the care packages they feel best suit their needs. As it stands, people with significant mental health issues, which could be better managed, even resolved, with specialist input, are denied this care and left to flounder in deteriorating health, for years.
- consider initiating an inquiry into the implementation of Shared Care Agreements across Wales with the aim of co-producing and ensuring compliance with improved guidance and practice. Given the numbers who, because of lack of NHS provision and excessive waiting times, have had to pay privately for a diagnosis and treatment plan, we see this as a vital step in facilitating better and more timely care. Our members tell us that this would be of particular benefit to autistic people and those with ADHD, especially women / AFAB who experience significantly longer delays to diagnosis than their male counterparts.

With regards to access to services for long-term chronic conditions, including musculoskeletal conditions, FTWW would first of all like to congratulate the Committee on prioritising this often-neglected aspect of health and related services. As a women's health equality charity, we would particularly like to see the Committee's focus in this area reflect the fact that a significant number of chronic conditions solely or predominantly affect women / AFAB and that there is a concomitant lack of research and investment in services which needs addressing during this Sixth Senedd.

Our points on this priority area echo findings and recommendations from research undertaken as part of the UK Rare Diseases Framework (3) despite the fact that many of the chronic conditions with which our members are living would not be considered 'rare' but, in some instances, relatively common. In the first place, we would ask that the Committee revisit Mark Drakeford (then Health Minister)'s assertion that the border between Wales and England would not prevent access to specialist services which were unavailable in Wales. As it stands, the system in Wales often prevents referrals 'out of area' both within and outside of Wales, something that is having a catastrophic impact on patient outcomes.

Generally speaking, the public understands that, as a relatively small nation, Wales may not be in a position to always provide tertiary level care close to home and that highly specialised services will likely need to be consolidated in one locale, whether that is in Wales or outside its borders. As an organisation, we would dispute the assertion that 'care closer to home' is always better and what all patients want. Whilst care closer to home is undoubtedly the ideal for routine services, for chronic, often complex, conditions, it runs the risk of denying patients the opportunity to access optimum care, potentially making their prognosis poorer and ultimately costing the economy more.

A survey of our members with chronic / recurrent health conditions revealed that 99% of respondents would prefer to travel to access a specialist / multi-disciplinary team or clinic than repeatedly be referred for less-specialised (and often, sadly, ineffective) services locally. Further, 100% of those respondents told us that they had never been offered the choice. Not only is the seemingly exclusive 'care closer to home' agenda impacting negatively on chronically unwell / complex patients, it also runs the risk of de-skilling the workforce because there seems little incentive for health boards to collaborate on research, or to direct funds, training, and innovation towards centralised hubs or centres of excellence, open and accessible to all patients in Wales. With the increasing use of remote digital technology in health services, it should actually be possible to develop hybrid models of care where patients only need to travel to centres of excellence for specialised procedures, investigations and the development of treatment plans. Meanwhile, ongoing monitoring, medication, and treatment can be delivered locally by advanced skills / specialist nurses and associated professionals who are able to facilitate regular contact with the consultant(s) farther afield.

As it stands, where such centres of excellence do exist in Wales, they will generally be operated by one health board alone and, in practice, only benefit their own population. Patients often experience a real reluctance on the part of their local health providers to refer 'out of area' to a more specialised clinician or service, partly, our members tell us, because consultants are unwilling to acknowledge patient need, and partly because the funds don't allow it. This leads to a lack of confirmed pathways to enable out of area referrals for patients who need them, even when NICE or equivalent guidelines make clear that these pathways are essential for better outcomes. The result is huge geographical variation in services and inequality of outcomes for patients.

We find this situation particularly pronounced in chronic and recurrent health conditions mainly affecting women where there is a historical lack of research and investment, largely because women's health (beyond maternity) has not been considered or seen as an area worthy of prioritisation and additional investment. Increasingly, evidence is coming to light that points to systemic male bias in clinical trials and diagnostic models, in addition to prejudicial attitudes in healthcare provision which see women's reporting of symptoms downplayed or dismissed. It is vital that these issues are acknowledged and addressed as a matter of urgency, not least because they create significant barriers to accessing appropriate services and have considerable implications for employment, financial security, and wellbeing more generally. In addition to the long-term health issues arising from diagnostic delay, a lack of confirmed diagnosis and

associated medical care or support also poses problems for employees needing to make the case for reasonable adjustments in the workplace and makes it more difficult for those unable to work to access benefits and social care.

We would call upon the Committee to:

- commission co-produced research into patients' experiences of living with and managing chronic and recurrent illness in Wales and commit to implementing recommendations
- commission co-produced research to investigate patients' experiences of gender bias in healthcare provision and services in Wales and commit to implementing recommendations
- acknowledge and address systemic issues in accessing healthcare, most notably that the 7 autonomous health boards in Wales often do not work together in the best interest of patients. Existing block-funding arrangements, where funds do not follow the patient, disincentivise the provision of tertiary services for patients 'out of area' and need to be re-examined
- call for an independent inquiry into the Individual Patient Funding Request process which we find to be poorly administered with significant variations in how it is utilised across Wales. As a mechanism it is inherently unfair, unwieldy, and time-consuming, as well as disempowering for patients and not in line with principles of shared decision-making. The IPFR as it stands is not well-suited to patients needing to access services out of area and, in many cases, medical professionals' reluctance to use it effectively makes it practically impossible for patients to access the care they need without a long, arduous, and stressful battle with their healthcare providers – a battle which can still be unsuccessful, even assuming the patient has capacity to engage in it
- re-examine the operation and make-up of the Welsh Health Specialised Services Committee and lead a consultation on how far its purpose, function, and remit should be expanded and a more co-productive approach to its activity adopted
- exert influence on medical schools in Wales to improve and co-produce with patients training for healthcare professionals in identifying and challenging unconscious bias, shared decision-making, women's health, and managing chronic illness more generally
- initiate an investigation into the degree to which health boards are embedding co-productive practices, as distinct from 'engagement' and consultation
- commence an audit of health boards' existing provision of care for chronic illnesses and how far, consistently, and effectively they are referring patients to specialist, multi-disciplinary centres of excellence. We would suggest that patients themselves have a role and voice in any such audit.

References

- 1) <https://www.ftww.org.uk/2021/wp-content/uploads/2020/11/FTWW-Manifesto-English-FINAL.pdf>
- 2) <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdeciles/wales/2017to2019>

<https://www.gov.uk/government/publications/uk-rare-diseases-framework>

Blaenoriaethau allweddol ar gyfer y Chweched Senedd

Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;**
 - b) social care and carers;**
 - c) COVID recovery?**
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Gwasanaethau iechyd

Health services

Women's Health

Fair Treatment for the Women of Wales (FTWW) is delighted to be working with the British Heart Foundation Cymru in facilitating a third sector coalition to draw up a Women and Girls' Health Quality Statement and Plan for Wales. Members of the Coalition range from independent patient advocates to condition-specific charities, UK-wide umbrella organisations, and Royal Colleges. We all share one ambition: to see women and girls' health rightly prioritised in Wales as it is now being in other UK nations. To do so will address underlying and multi-generational health inequalities and disparities affecting females, negative and dismissive attitudes which have resulted in horrifying reports like the 2020 Cumberlege review, 'First Do No Harm' (1) and see practical steps taken to improve medical research, efficacy of treatment, and service provision across the country.

Women make up some 52% of the population in Wales and are more likely than men to be primary care-givers for younger and older generations (2) whilst also making up almost 50% of the UK workforce, with rates of women in full-time employment rising faster than that of men (3). Given these significant responsibilities, women's health is fundamental to the well-being of Wales as a nation and yet, historically, it has been neglected: women's health – including maternity provision – was not mentioned in Welsh Government's existing long-term plan for health and social services, 'A Healthier Wales' (4), despite the stated aim of becoming a 'feminist government' (5) and undertaking a Gender Equality Review which saw health as a top priority for women across Wales (6).

Traditionally, any consideration given to 'women's health' will focus mainly on maternity care. Whilst this remains of vital importance, particularly given the historic failings in maternity services at Cwm Taf and alarming disparities in maternal mortality rates in black and minority ethnic women, we note the lack of emphasis on gynaecological care / services and, even more so, other disease areas or issues which disproportionately and negatively impact females. Health conditions which solely affect women and those assigned female at birth, such as endometriosis, costing the UK economy £8.2 billion annually (7), and menopause which will affect 52% of the population at some point in time, auto-immune conditions, cardiovascular diseases, osteoporosis, and dementia, chronic pain and fatigue, hypermobility and connective tissue disorders, amongst others, incur a significant cost burden to Wales. The ONS reports that women live fewer years in good health than men (8) and are more likely to be in poverty, requiring both social and financial support. These inequalities are likely to be compounded for those experiencing intersectional barriers which would include legally protected characteristics and neurodivergence.

Currently, there is a Welsh Government-funded women's Health Implementation Group and Programme, three years into its 5-year term to deliver on a remit limited to vaginal mesh and tape, faecal incontinence, and endometriosis. The funding is £1 million per annum which is wholly inadequate to tackle severe disparities and failings in care across Wales for endometriosis alone, without even touching upon the vast array of health conditions impacting significantly on women and AFAB and for which urgent action is needed to address inequality of outcome. There is an essential need for long-term oversight and joined-up strategic thinking on women's health which currently isn't being met.

In light of the above, we would call upon the Committee to support the following women's health-related priorities:

- the development and implementation of a Women and Girls' Health Quality Statement and Plan for Wales currently being developed by the third sector coalition FTWW and BHF-C are facilitating which will cover a wide range of conditions and disease areas and which has the support of Welsh Government's Women and Children's Health Branch
- a life-course approach to women's health which includes but, crucially, extends beyond the traditional focus on maternity
- consistent high-quality service provision, including specialist tertiary care, accessible to residents the length and breadth of Wales
- co-produced research into the impact of women's health conditions on patients and the wider population, investment in clinical trials, and disaggregation of emerging data by sex and gender
- investment in enhanced training for healthcare professionals in Wales

- a public health approach which focuses on education / awareness and prevention and early intervention in women's health
- encouraging the development of appropriate workplace policy and practice
- sustainable resourcing of specialist third sector organisations enabling a fully co-productive approach to women's health strategy and service design in Wales
- integration of the women's health implementation group (WHIG) and programme (WHIP) into long-term NHS Wales planning
- ensuring that decision-making and activity undertaken by the WHIG or equivalent is fully co-productive in its approach – *'nothing about us without us'*

References:

- 1) https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf
- 2) <https://www.carersuk.org/news-and-campaigns/features/10-facts-about-women-and-caring-in-the-uk-on-international-women-s-day>
- 3) <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/employmentintheuk/latest>
- 4) <https://gov.wales/healthier-wales-long-term-plan-health-and-social-care>
- 5) <https://gov.wales/sites/default/files/publications/2020-03/advancing-gender-equality-plan.pdf>
- 6) <https://chwaraeteg.com/wp-content/uploads/2019/09/Gender-Equality-a-roadmap-for-Wales.pdf>
- 7) <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>
- 8) <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdecileswales/2017to2019> (Section 4)

An independent, statutory NHS Executive for Wales

An independent body which has statutory powers and authority to audit activity and hold health boards to account regarding service variation and inequality of access is a vital mechanism in improving patient care.

We see such a body as providing invaluable recourse for patient representative bodies and advocates looking to highlight, challenge, drive change, and co-produce solutions to health inequalities, of which geographical location is one.

We would expect an independent and statutory NHS Executive to support and demonstrate the co-productive activity required for patient-centred strategic change, as well as playing a fundamental role in guiding service design, ensuring implementation, and conducting evaluation across Wales. This is a forward-thinking and preventative approach, unlike complaints processes and inquiries which are, by definition, retroactive.

An independent statutory body would have the power to instruct better data-gathering and use of evidence to inform service development, audit services and patient experience across Wales, ensure appropriate investment in training and service delivery, and oversee the implementation of joined-up pathways for all patients in Wales, irrespective of geography. This would eliminate the existing disparities in care which underpin inequalities of outcome for Wales's population.

Without statutory powers, any executive function will continue to be stymied in its efforts to put patient care and experience at the centre of the NHS offer, limited as it already is to issuing advice and guidance but with little ability to ensure that recommendations are actually put into practice and are improving outcomes.

We would call upon the Committee to:

- assert its influence on the Health Minister, NHS Wales, and health board executives to establish an independent NHS Executive with the statutory powers to make a real and positive difference to patient experience and outcomes across Wales.

Adfer yn dilyn COVID COVID recovery

Rehabilitation from Long-Covid is of key concern to our members, with evidence showing that it is disproportionately affecting females. Much like other auto-immune conditions and chronic post-viral / fatigue syndromes, approximately 80% of sufferers are expected to be women. Given the historical prejudices these patients report, with symptoms often dismissed or erroneously attributed to a psychological cause, we are keen that the Committee seek assurances from both practitioners and service providers that patient reports are being taken seriously and onward referrals made expeditiously.

As per section 1, and the Committee's focus on chronic illness, we would like to echo the need for a hybrid model of care for Long-Covid patients, where access to specialist multi-disciplinary hubs is facilitated, with less specialised / more routine interventions such as pain management, physiotherapy, and CBT delivered locally, as part of a bespoke treatment plan devised by specialists. As such, we would call on the Committee to engage meaningfully with patient groups and advocates to explore and facilitate their needs.

We also see Covid recovery as an opportunity to re-examine those issues highlighted earlier in this submission, including collaboration between health boards, upskilling of medical professionals, and patient-centred care where the patient is empowered to exercise voice, choice, and control over the type and location of care they receive. We would call on the Committee to strongly reiterate the need for an independent NHS Executive body with statutory powers which has the authority to audit activity and drive change, as well as ensure easily accessible and meaningful mechanisms are in place for patients to report their experiences and outcomes. This is distinct from the complaints process but is part of meaningful co-productive decision-making and strategy, something that if properly resourced and implemented has the potential to make a real, lasting, positive change for patients in Wales.

Finally, with regard to recovery from Covid, we would urge the Committee to recognise the ongoing role the third sector, particularly grassroots organisations, have played throughout the pandemic – and continue to play – in supporting and advocating for their communities. Not only have organisations like FTWW provided essential peer support and information during the Covid crisis, they have also been an invaluable source of evidence and learning for public bodies, including Welsh Government, local health boards, and local authorities.

The pandemic has very much highlighted pre-existing inequalities and gaps and demonstrated how vital co-production is to achieve better, fairer, more informed service delivery. In order to continue providing this level of input to beneficiaries, both service-users and providers, we would call upon the Committee to prioritise making long-term, sustainable funding accessible to organisations like FTWW as an investment in the wellbeing of future generations.

Unrhyw faterion eraill

Any other issues

C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?

Q3. Are there any other issues you wish to draw to the Committee's attention?

i) We would like to echo the Welsh NHS Confederation's call for an inquiry across all Senedd Committees on tackling health inequalities in Wales. Meaningful progress will require a consistent and joined-up approach across all sectors.

It is our belief that to make recommendations a reality, Welsh Government leadership on tackling the root causes of health inequality is vital. This will ensure sustained, focused, and coordinated action across all Government departments.

Long-term investment in preventing health inequalities will be needed and should be targeted at infrastructure and services that offer sustainable and co-produced solutions to the underlying causes of health inequalities.

The Welsh Government should facilitate an enabling, responsive, and innovative operating environment that includes citizens, communities, public bodies, not-for-profit and third sector, and the private sector as equal partners. Priorities should include giving people a greater voice in defining solutions and making partnerships fit for purpose, as per the Welsh Government's commitment to co-production at every level.

We would urge all of the Senedd's Committees, including the Health and Social Care Committee, to work together on conducting an inquiry into how far the Welsh Government's departments are tackling the root cause of health inequalities. The inquiry should lead to recommendations, outcome measures, and timescales for improvement.

ii) In line with Welsh Government's commissioned report into the impact of Covid-19 on disabled people in Wales (1), we would urge the Committee to consider how it might review organisations' compliance with both the Public Sector Equality Duty and Socio-Economic Duty and their execution of Equality Impact Assessments. In particular, we would urge the Committee to focus on measures to ensure on-going co-production of these mechanisms, at every level of service design, delivery, and evaluation.

iii) Finally, we would like to assure the Committee that FTWW: Fair Treatment for the Women of Wales would be pleased to assist members with any relevant aspects of its work.

References:

1) <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19>