



**FTWW, Fair Treatment for the Women of Wales is a patient-led women's health equality charity, providing support, information and advocacy for women across Wales who are living with chronic or recurrent health conditions. We empower women to share their lived experiences and facilitate opportunities for them to get involved in the design, delivery, and evaluation of health services locally and nationally.**

### **1.Awareness and understanding of the Act and its implications.**

1 Arguably, the general public has not heard of the Act, or only vaguely, and will not be aware of its implications for them as citizens and / or their interaction with public services. Likewise, whilst public bodies and Welsh Government officials will of course know of the Act, their in-depth knowledge and appreciation of its principles and commitment to enacting them seems variable.

2 As a women's health equality organisation with a very active online support and information group, we will have shared relevant portions of the Act with our membership, as well as any opportunities to get involved in engagement exercises / events pertaining to it. We will also refer to the Act in our correspondence with civil servants, ministers, and / or health board executives as a lever in asking for patient involvement in the development of strategy or service design.

3 As an organisation, we believe very strongly in the efficacy of co-production, so the Act has given legitimacy to our campaigning in this regard. Nevertheless, there is still, in our experience, limited and varied understanding of what co-production means and entails in practice, and certainly a failure to explore mechanisms that would make it a reality at every level of (health) service design and delivery, including the training and assessment of healthcare professionals. Too often, there is a misapprehension that 'consultation' or 'engagement' equates to co-production – it does not.

4 On the ground, if and when we raise the topic of the Act with our members, they will ask how it can be used as a tool to enforce positive changes to the health services they receive. Our members are particularly keen to understand how two of the Wellbeing Goals, 'A More equal Wales' and 'A Healthier Wales' are being implemented, given their consistently poor experiences of women's healthcare in Wales. They ask to what extent the Act can be used to enforce Welsh Government's commitment to the prudent healthcare principles of 'early intervention' or 'prevention' of escalating ill health, and consistency of access to specialist services across Wales. Most especially, members want to know what easily accessible mechanisms are in place to enable them to utilise the Act in challenging a system which is not meeting their needs.

5 Our members repeatedly ask how serious Welsh Government is about implementing the Act when the NHS system in Wales consists of 7 fairly autonomous health boards, a system which perpetuates variation in service provision and inequality of access and outcomes, and which largely prevents access to services 'out of area'. Previously when, as advocates, we have put this question to Ministers, the answer has been 'judicial review' which is unfeasible for individuals or grassroots organisations like ours. Whilst the Equality and Human Rights Commission in Wales may have some capacity to bring cases, this is much reduced.

6 Information about the Act, the benefits or rights it bestows on citizens and / or service-users, and how to utilise them, needs to be as well known to people as is the location of their GP. It needs to be part of teaching in schools, and citizens need to be both advised and supported to ensure the practical application of it in their everyday lives. There needs to be action on ensuring public bodies fully appreciate its value and are legitimately incorporating its tenets into their work rather than viewing it as a tick-box exercise.

## **2. The resources available to public bodies to implement the Act and how effectively they have been deployed.**

7 We would like to see health boards across Wales committing both practically and financially to co-productive practices in their design, delivery, and evaluation of services.

8 In North Wales, Betsi Cadwaladr UHB's Women's Directorate and FTWW work together in this process, primarily through the mechanism of 'Gynaecology Voices', a co-chaired forum where patients will initiate and work through service development with clinicians and executives, including business cases, patient information, implementation and audit. However, there has been no financial resourcing made available to FTWW to ensure consistency and sustainability of input in this regard.

9 Ideally, we would wish to replicate this work within the other 6 health boards but, as a grassroots organisation and small charity, we need resourcing to make it happen, something

that should come from health boards but be mandated by Welsh Government as part of its commitment to the Act. Co-production does have costs attached to it – but they should be seen as an investment in ensuring services which are fit-for-purpose and ultimately more cost-effective, exactly as outlined by the Act.

### **3.Support provided to public bodies by the Future Generations Commissioner**

10 We would like to have more opportunities to engage with the Commissioner and team from a grassroots / patient-led organisational perspective, so that the Commissioner is able to incorporate more advocacy into her work in supporting public bodies.

11 By formalising processes of collaboration with citizens / service-users, those aspects of the Act which citizens see as not working well in the public sector can be more effectively audited, with mechanisms for ongoing improvement and evaluation devised co-productively.

12 Public bodies need examples of good practice and then to be assisted in emulating or developing their own – again, with co-production at the core. The Commissioner and team need to be given the means to be pro-active in this regard, not just with support, and assistance (ie, the ‘carrot’) but also holding public bodies to account when things aren’t being done (the ‘stick’). For example, when it comes to Equality Impact Assessments, public bodies’ completion of them needs to be meaningful – what evidence can they provide to indicate their being undertaken co-productively? If they’re not being done this way, the Commissioner and team could be working with service-users to develop protocols which enable them to be so and then monitoring their continuation and effectiveness. Perhaps these practices need to be incentivised, with action taken if protocols aren’t followed.

13 Additionally, the Commissioner and team needs to be looking at ways of enabling citizens and their representatives or advocates to challenge public bodies if their policies and practices are not in line with the Act.

### **4. The leadership role of the Welsh Government.**

14 Welsh Government has a role to play in the implementation of the Act, not just in terms of developing the legislation and leaving it to public bodies to implement it (or not) in various ways of their own devising but also in terms of their own practice.

15 Co-production at every level includes Welsh Government; they have a vital leadership role to play in setting a good example to public bodies like health boards and local authorities. Too often in all these settings, citizen representatives / groups are kept at arms’ length, only allowed to be involved in decision-making processes up to a certain degree. Alternatively, there is a tokenistic level of involvement where, for example, public services boards are merely

required to have a single citizen representative at the table who is significantly outnumbered, often not adequately supported, and ill-equipped to advocate for the huge number of issues raised by distinct communities.

16 In addition, in some quarters, there does remain a somewhat paternalistic view that citizen advocates are not sufficiently knowledgeable to play a role in all aspects of decision-making. This needs to be challenged, even at the highest levels, where mechanisms to work with citizens need to be both created, resourced, and audited.

## **5. Any other barriers to successful implementation of the Act (e.g. Brexit, COVID, etc.).**

17 Again, focusing on the Act's tenet of co-production and, tangentially (as per the Social Services and Wellbeing Act) 'citizen voice and control', executives' response to the Coronavirus pandemic has, in many instances, resulted in the suspension of citizen involvement in strategy and service design / delivery.

18 There have been suggestions that involving citizens / service-users is too time-consuming and / or not sufficiently agile, or a paternalistic misconception that service-users aren't resilient enough to cope with discussions about illness and death. In actuality, the pandemic has demonstrated how absolutely vital co-production is to ensuring things work properly, are inclusive, and efficient, from things as 'basic' as deciding on content of food parcels and how to physically deliver them, to not fully considering the impact of policy decisions or legislation on disabled people. Had co-productive principles and mechanisms to ensure citizen involvement been fully and properly embedded in all public bodies' departments from the start, these issues likely wouldn't have arisen.

## **6. How to ensure that the Act is implemented successfully in the future.**

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- Make information about the Act readily and universally accessible in a range of places, including educational and healthcare settings
- Ensure that the Act has 'teeth' and is being enforced, not just by way of judicial review but by adequately resourcing agencies like the EHRC and other advocacy organisations, so that they have the means to challenge bodies / policies where the principles of the Act are not being upheld
- Develop with citizens easily accessible mechanisms for them to make use of the Act, including the means to ask questions of service-providers, get involved, and challenge

public bodies / service-providers themselves, so that they can see the Act working in real-life terms for them rather than its being seen as lofty and unattainable

- Provide public bodies with real-life examples of good practice in policy-making and service design / delivery, and allocate them Act 'representatives' who can work consistently with them to ensure that its key tenets are upheld at every level of their work. This would include ensuring co-productive practice and should apply to Welsh Government just as much as any other public agency
- Focus on the need for public bodies to co-produce solutions and for there to be regular and independent auditing of activity; both incentivise the practice of co-production and hold to account when it isn't happening
- Adequately resource and support service-user-led bodies who are facilitating co-productive practice with public bodies.