

CASE STUDY: FAIR TREATMENT FOR WOMEN IN WALES



BACKGROUND

Fair Treatment for Women in Wales (FTWW) emerged from a Face Book group set up in late 2014 to share information about women's health care provision and become more established women's and girls' patient-led organisation in 2015 for those who require practical help, support and advice on women's related conditions and how to deal with health services. The organisation was developed originally to help women with Endometriosis† and campaign for better access and services in Wales. FTWW have now campaigned to improve support and services for women who have experienced, for example, a miscarriage and for women who experience the adverse effects of the Menopause. The organisation is also campaigning for better service for women who have Ehlers Danlos Syndrome*, Autism and experienced perinatal mental health issues. Their online closed platform attracts 700+ members.

†*Endometriosis: This condition is comprised of tissue similar to that lining the womb being found elsewhere in the body, causing inflammation, bleeding, pain, organ dysfunction, and, sometimes, infertility. It usually affects girls and women of childbearing age. It is less common in women who are post-menopausal (www.nhs.uk).*

**Ehlers Danlos Syndrome: Rare genetic condition which affects the connective tissues.*

Debbie Shaffer, CEO and founder of FTWW winning two Chwarae Teg Womenspire '18 awards



INTO ACTION

FTWW main aim is to work together to achieve better health and support services for women. This has led to FTWW initiating several petitions to lobby the Welsh Government; highlighting gaps in women's healthcare provision and how to address them. FTTW has no specific funding and fund raises through its membership to address health inequalities and is an excellent example of citizen co-produced action; **'getting their voice heard....being in control'** and that change in thinking can happen through collective proactivity. It was felt that it was important to:

- **Empower women:** FTWW is a participatory organisation which works with members to seek feedback on various issues and is a **'constructive, proactive group of women'** who have come together to discuss topics in a comfortable environment. The key to the success of FTWW campaigns has been how the organisation has invested time and energy in supporting women to act, to question and to advocate for themselves.
- **Unleash the power of the collective voice:** It was recognised that many hundreds of women were experiencing the same issues and barriers in accessing healthcare services, each having **'individual battles'**. The combined voice was felt to be the most powerful co-produced tool members had in influencing change and developing specialist services.
- **Learning through taking action:** The proactivity of the members; seeking out information and sharing experiences has been an important feature **'learning along the way'**, disseminating what they have learned, and giving other women to tools and evidence to access specialist clinical pathways and to address gaps in women's health care provision.

WHAT HAS WORKED WELL

- **The power of the collective:** While individual voices were the catalyst, the collective voice of members of FTWW has raised the profile of women's health-related issues, particularly issues which are seen to be sensitive issues and people not wanting to discuss, such as menopausal symptoms and incontinence. FTWW have had items on BBC Wales News; raising the profile of the lack of Endometriosis and Miscarriage specialist services in Wales.
- **Identifying and co-producing with interested clinicians:** FTWW worked with specialists, who were also looking at similar gaps and lobbying Welsh Government to set up Task and Finish groups to look the development of specialised services in Wales, with patients taking the joint lead to build the evidence base and recommendations to the Welsh Government. As a result, the Welsh Government invested £1m into a dedicated pelvic physiotherapy service in Wales rather than patients, for example in North Wales, having to access this across the border.
- **Online profile:** FTWWs online activity, through a closed Face Book group, has supported members who were previously isolated, lacked information and were uncertain how to access specialist health care.

CHALLENGES

- **Disparity of provision:** Uncertain clinical pathways and lack of centres in Wales for certain specialisms such as Endometriosis has led to inequality and unfair treatment. There were differences between North and South Wales, with women more likely to access a specialist service, if one existed, in the south.
- **Working your way through online information:** Information provision by UK third sector organisations tends to be England-centric and misleading for patients living in Wales where like for like services are not available. Where such services exist, there is unequal access to tertiary specialist services outside Wales. One member who lived on the border moved to a GP practice in England to access specialist services only available in England. FTWW
- **Shared decision-making:** FTWW felt that some clinicians were reluctance to enter into shared decision-making arrangements with patients as clinicians saw it as a **'loss of power, their own power'**. FTWW considered that it should be an enabling process where sharing power does not mean that you are losing control and that they are not giving up **'their little piece of the power pie'**.
- **Removing public perceptions:** It was felt that having an 'invisible' disability or chronic condition often led to discrimination and a lack of public understanding if you **'look like you are in perfect health'**.

BARRIERS

- **Referral pathways:** Uncertainty as to the system to access specialist services was a considerable obstacle for women in Wales with specific women-related conditions. It was considered that GPs were not always aware of referral pathways particularly those pathways which led to access across the border. Working the way around health systems was problematic and frustrating. It was felt that there was a lack of transparency and a reluctance from clinicians to share information with patients, which lead to mistrust, with clinicians not listening to patients needs and concerns.

'We felt discriminated against.... it's a world-wide phenomenon.....medical textbooks are decades old and women's health is kind of lumped into one chapter; there is a lot of stigma around gynaecological issues and there is a kind of normalisation around pelvic pain'.



SUCCESSSES

- **Co-producing:** A key success factor of FTWW is their ability to bring together like-minded women wanting to make a difference and raising awareness of women's health inequalities co-producing and drawing together their members views on several specific health conditions which affect women. FTWW have successfully compiled, contributed and authored patient/service-user reports for the Welsh Government. Their work on the lack of Endometriosis specialist services led to the Welsh Government and NHS Wales to establish a Task and Finish Group to look at developing services for Welsh patients. Because of FTWW identifying the needs and gaps in Endometriosis provision the Welsh Government released a statement (October 2018) on the publication of the Endometriosis Task and Finish Group Report highlighting the role of the FTWW report in initiating the discussion and subsequent recommendation to **'improve Endometriosis services and provide better outcomes from women'** (Gething, 2018).
- **Gaining confidence:** Members had learnt from one another in a supportive environment with the Chief Executive Officer leading the way instilling confidence by giving members the means to share, discuss and take collective action to highlight women's health inequalities. Members interviewed for this case study enthused passion, were tenacious and wanted to make a difference through being proactive. Several members had the confidence and took up the banner around other women's-related health issues. One member was a doctor but felt that she was not taken seriously despite having nearly finished her GP training before she became ill, but that being a member of FTWW gave her the confidence: **'I was passionate about being able to say that you need to exclude these conditions before you diagnose this other condition. You know Debbie (CEO of FTWW) has given me the confidence that I do have some knowledge and I do have something to offer'**.

Many members have been inspired to act through gaining confidence rather than disengage; that making a difference matters for other women and that it felt **'less insurmountable obstacle'** in Wales. However, they were mindful of one of their members who is a doctor and had worked 10 years in the NHS until she become unwell that if she could **'navigate the NHS how an earth is anybody else supported to do so?'** The success of FTWW was their ability to help people navigate the clinical specialist pathways or identify where such pathways needed to be established through their proactive approach to deal with gaps in women's health care provision.

WHAT HAS BEEN LEARNT?

- **Developing the evidence base:** Generating and distilling the evidence of need informed through women's stories which identified the importance of addressing women's health care inequalities. Members learnt through co-producing the power in collecting powerful stories of unmet need.
- **Being well-informed:** FTWW began with one voice, one person's experience and battle to access a special health service. She used many avenues through to contacting the First Minister to highlight concerns and gaps in provision which also highlighted that not all clinicians working in women's health know about existing referral pathways and where know often asked patients to complete an Individual Patient Funding Request when such a request was not necessary. One member felt that had she not contacted FTWW she would still have been on the wrong clinical pathway. Poor communication was at the root of not being able to access specialised services.
- **Using current health and social care legislation:** FTWW recognised the importance of legislation as a lever for change. The Social Services and Well-being Act gave them the means to voice their concerns, take control over their own lives and co-produce, given legitimacy to their work and collective effort.

CONCLUSION

FTTW has clearly demonstrated the power of co-producing as individuals and more powerfully as a collective. The organisation has raised the profile of the inequalities in women's health care provision, especially specialist services which are not accessible in Wales. The core team and members of FTTW have learned through action to work effectively with the Welsh Government to develop strategies and identify pathways to services.

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