

# **Voluntary Organisations Disability Group Representation to the Women's Health Strategy: Call for Evidence**

**June 2021**

## **About VODG**

VODG is the national infrastructure body representing organisations within the voluntary sector who work alongside disabled people. Our members' work is focused on enabling disabled people of all ages to live the lives they choose. VODG believes that an ambitious, trusted and vibrant voluntary sector that works together plays a unique role in achieving this aim. VODG members work with around a million disabled people, employ more than 85,000 staff and have a combined annual turnover in excess of £2.8 billion.

VODG welcomes the opportunity to submit this representation to the Department for Health and Social Care's (DHSC) call for evidence on the Women's Health Strategy. This submission is informed by engagement with our member organisations via a dedicated meeting on this consultation, and further membership engagement and follow up. We use this paper to draw out the views of our members – voluntary sector providers of disability care and support. Further to this point, we approach this submission through two lenses: the first as providers of services to disabled women, the second as employers of disabled women and more widely, as providers in a sector that is one of the biggest employers of women, disabled and non-disabled.

## **1. Context**

There are 14.1 million disabled people in the UK, representing 21% of the population and 19% of working age adults.<sup>1</sup> Twenty-four per cent of females (7.8 million) reported a disability in 2019 to 2020, an increase from 19% (6.1 million) in 2009 to 2010. In recent years, most age groups have seen a higher proportion of females than males reporting that they are disabled.<sup>2</sup>

The provision of essential services to disabled people in ways that promote independence, choice and control, as well as supporting their carers is a statutory obligation. The hallmark of a fair and equitable society includes fully meeting people's needs and enabling disabled people to have full choice and control over their lives, and to be included in society.

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<sup>1</sup> Department for Work and Pensions (2020) *Family Resources Survey*.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/874507/family-resources-survey-2018-19.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874507/family-resources-survey-2018-19.pdf)

<sup>2</sup> Department for Work and Pensions (2021) *Family Resources Survey: Financial Year 2019 - 2020*  
[www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#disability-1](http://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#disability-1)

Services to enable disabled people in England to live independently are delivered in a variety of settings and care and support is provided via a diverse range of services. The onset of the pandemic has shone a bright light on the valuable work that social care workers and their organisations carry out across the country to support people in vulnerable circumstances each and every day. In England, 82% of the workforce identifies as female<sup>3</sup> and women care workers have been massively impacted by the pandemic in numerous ways, including to their mental health and wellbeing.

## 2. Introduction

A tailored response to women's health is vital because we know that currently the health care system is not fully meeting the mental and physical health needs of women. Additionally, a tailored response to disabled women's health and wellbeing is necessary because there are additional layers of systemic bias and disability discrimination, compounded by gender discrimination, experienced by disabled women that means health issues are not being addressed or are being overlooked. This has been further exacerbated by the coronavirus (COVID-19) pandemic.

VODG welcomes the government prioritising the health of women and girls by launching this new strategy and believes that it is essential that women, and those populations of women who are further marginalised, including disabled women, are involved in the design, implementation, and monitoring of the new Strategy as it relates specifically to that population group. For example, disabled women should be involved in a review of existing health policy and should help inform new and improved service provision. Our engagement with VODG members also highlighted a need for greater disability awareness among health professionals and VODG believes that through the development of the Women's Health Strategy, there are significant opportunities to involve disabled people and not for profit providers of care and support services (as employers of support workers) in the design and delivery of training and education that will lead to better outcomes for disabled women.

This submission seeks to address some of the core themes outlined in the DHSC consultation scope, alongside putting forward recommendations to government.

## 3. Placing women's voices at the centre of their health and care

A prevailing theme during our engagement with members around putting women's voices at the centre of their health and care was that of the presence of bias and assumptions among healthcare professionals when consulting with disabled women, and which leads to a sense of not feeling 'heard'. VODG members put forward examples of either themselves, or disabled people they support, not being able to access sexual and reproductive services and being told such services were irrelevant to them because of their disability (in reference to accessing contraception,

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<sup>3</sup> Skills for Care (2020) *The size and structure of the adult social care workforce in England, 2020*. [www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2020.pdf](http://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2020.pdf)

for example) or because that service would be too distressing to provide without considering appropriate adjustments to ensure access to vital health services (in the example of cervical screening for women with learning disabilities). This is simply unacceptable and without significant work to shift perceptions and remove bias, disabled women will continue to encounter discrimination in not having their voices heard.

VODG members, many of which provide support and care services to women with learning disabilities and / or autism who may be unable to express health concerns independently, also reported that the importance of the role of the support worker as advocates for the disabled people they support, is undervalued by health professionals. Some gave examples of their input being dismissed and when challenging a health professional's advice or diagnosis, which failed to 'see' and understand the needs of the person being treated, being seen as 'difficult'.

Alongside this is the issue of accountability and lack of clear and accessible mechanisms that allow women, disabled and non-disabled, and / or their support workers, to challenge a health professional when it is felt that their voice is not being heard or that the representation of that person is being dismissed. Clearer, more accessible information and advice on how to make complaints and address poor, or discriminatory practice, is required.

Greater disability awareness among healthcare professionals is required as well as more support for the role of support workers as advocates for disabled women. Furthermore, having experts by experience as trainers for disability and health issues should be mandatory. Alongside this is the need for appropriate training for support workers to help identify and understand female-specific health issues, for example the symptoms of menopause, so that they can adequately brief health professionals as well as offer appropriate care to the women they support. There exists a number of practical and progressive initiatives across the country that achieve such aims (including many facilitated by VODG members) but they are often dependent on funding and / or are regionally based.

***Recommendation: The Department of Health and Social Care to increase and improve disability awareness, and remove bias, among healthcare professionals through appropriate training and educational programmes that is informed by lived experience.***

***Recommendation: The Department of Health and Social Care to ensure provision of funding and grants that encourage and enable initiatives which promote understanding of female-specific health conditions among social care support workers.***

***Recommendation: The Department of Health and Social Care to commission a review of good practice, and emergent ideas, being led by providers that are addressing women's health and inequality. To also identify initiatives that could be adopted more widely and/or scaled up.***

***Recommendation: The Department of Health and Social Care to provide grants to user-led disability charities to deliver a programme of work to support awareness raising, information and education to disabled people.***

#### **4. Improving the quality and accessibility of information and education on women's health**

As a membership body representing more than 100 voluntary sector providers of disability services to people with sensory and / or physical disabilities, people with learning disabilities and / or autism, and people with complex health conditions, VODG believes accessibility and accessible information is an essential component in improving how healthcare information is accessed and understood.

The Accessible Information Standard (AIS) 2016 was introduced by the government to ensure that people with a disability or sensory loss are given information in a way they can understand. It is now the law for the NHS and adult social care services to comply with AIS. It is an excellent initiative that is, however, not being properly implemented.

The basic standard of accessible information, so often produced to tick a box, is, in fact, not always very accessible. Easy Read information requires a level of literacy, or access to someone who can read. Deaf women face additional barriers when attending healthcare appointments, which has been further exacerbated during the coronavirus (COVID-19) pandemic and the routine use of telephone consultations.

Added to these barriers, are often cultural and / or language barriers. VODG members reported that for many of the women they support (and for some, many of the women they employ), English is not their first language, and they are not from a White, British background. These barriers mean they often face additional discrimination in how information is presented to them and as such, often do not access healthcare services completely or do not fully understand the information provided to them.

The role of the support worker was further reinforced in response to this theme. As messengers of information to women they support, particularly people with learning disabilities and / or autism, their advocacy role is critical both in presenting information to health professionals but also in providing information to the person supported.

VODG has produced materials for support workers to enable them to engage with health professionals and our experience shows that these have been widely welcomed and adopted across the system. The resources are an enabling resource for support workers, and we also know that health professionals welcome these frameworks to support joint working. For example, 'Preparing to visit a doctor to talk about psychotropic medication'<sup>4</sup> enables support workers and people with a learning

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<sup>4</sup> Voluntary Organisations Disability Group (2017) *Preparing to visit a doctor to talk about psychotropic medication*. <https://www.vodg.org.uk/wp-content/uploads/2017-VODG-Preparing-to-visit-a-doctor-to-talk-about-psychotropic-medication.pdf>

disability and/ or autism to prepare for medication reviews. For people with a learning disability, this resource was supported by an awareness raising card game.<sup>5</sup> This work was commissioned by NHS England and NHS Improvement.

***Recommendation: The Department of Health and Social Care to ask the Care Quality Commission, and its regulatory partner Ofsted, to undertake a thematic review across health, adult social care and children's social care assessing the implementation of the Accessible Information Standard and to make recommendations.***

## **5. Ensuring the health and care system understands and is responsive to women's health and care needs across the life course**

VODG welcomes the life course approach that the Women's Health Strategy takes and the focus on understanding wider determinants of health and the opportunities for preventative action.

A strong theme that arose during our discussions with members was that of discrimination and bias in relation to disabled women and sexual and reproductive health services, and which continues to lead to health inequalities for disabled women.

In terms of breast and cervical screening, evidence suggests that uptake of breast screening is lower in women with learning disabilities compared to the rest of the population. Public Health England has recognised that women with learning disabilities can face many barriers to accessing screening, including lack of understanding which prevents them making an informed choice about whether or not to accept their invitation.<sup>6</sup>

Research conducted by Jo's Trust showed that 63% of the disabled women they surveyed were unable to attend cervical screening because of their disability. Furthermore, many women reported assumptions being made about sex and intimacy as a result of their disability, with some even being told they are not at risk of cervical cancer and that cervical screening is not necessary for them. 20% of respondents said that it has been assumed that they are not sexually active because of their physical disability.<sup>7</sup> VODG members also reported that women they support have been denied contraception by GPs because of assumptions made about their disability. Further to this, is members reporting seeing that disabled women face more barriers to enjoying sexual relationships compared with men they support.

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<sup>5</sup> Voluntary Organisations Disability Group (2019) *New edition of STOMP game launched*. [www.vodg.org.uk/news/new-edition-of-stomp-game-launched/](http://www.vodg.org.uk/news/new-edition-of-stomp-game-launched/)

<sup>6</sup> Public Health England (2019) *NHS Population Screening: Inequalities Strategy*. [www.gov.uk/government/publications/nhs-population-screening-inequalities-strategy](http://www.gov.uk/government/publications/nhs-population-screening-inequalities-strategy)

<sup>7</sup> Jo's Cervical Cancer Trust (2019) *We're Made to Feel Invisible*. [www.jostrust.org.uk/our-research-and-policy-work/our-research/barriers-cervical-screening-physical-disabilities](http://www.jostrust.org.uk/our-research-and-policy-work/our-research/barriers-cervical-screening-physical-disabilities)



Again, through discussion of this theme, it is clear that there is a need for greater disability awareness among health professionals, including around the reasonable adjustments that can be made to enable disabled women to access preventative screening services.

Menopause also came up as an issue for women drawing on social care services and specifically, that accessible information is not being provided to women with learning disabilities because health professionals are overlooking symptoms or assuming that those women will not understand, or do not need to know about menopausal symptoms. In addition, members report instances where menopausal women they support are not receiving medication or medical support for the changes taking place in their body. As such, it is suggested that more questions, specific to female-only health conditions such as the menopause, are included in the annual health check and other relevant questionnaires.

Support workers were, again, cited as important in ensuring the system understands and is responsive to disabled women's health, particularly women with learning disabilities and / or autism as they can often help with early and preventative action. A person's support worker often knows what 'good' looks like for that person and can identify and observe changes in health, for example the onset of menopause symptoms, and can flag these with a health professional. However, for such support to be effective, workers need also to be trained and knowledgeable about specific health conditions and appropriately trained to attend, as appropriate, women's health appointments and advocate on their behalf. A further benefit to this would be that support workers, predominantly women, will learn about, and understand, health conditions that they too will likely experience.

Members also expressed views that the rollout of learning disability nurses has been a positive development in terms of helping to ensure the health and care service is responsive to the needs of people with learning disabilities. VODG would like to see this taken further with the development of more health professionals with specialist learning disability, autism, and complex needs expertise. Training for such roles should include a focus on female-specific health conditions in order to build understanding and help reduce health inequalities among disabled women in the longer term.

***Recommendation: The Department of Health and Social Care to ask NHS England and NHS Improvement to review and expand the annual health check to ensure more questions around female-specific health conditions are included.***

## **6. Maximising women's health in the workplace**

In October-December 2020, there were 2.6 million disabled women in work, an employment rate of 53.1%.<sup>8</sup> Under the Equality Act 2012, employers must make

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<sup>8</sup> House of Commons Briefing Paper (2020) *Disabled people in employment*.  
<https://commonslibrary.parliament.uk/research-briefings/cbp-7540/>

reasonable adjustments to make sure workers with disabilities, or physical or mental health conditions, are not substantially disadvantaged when doing their jobs.

VODG members expressed concerns that there exists a general lack of understanding around what making reasonable adjustments means and the form reasonable adjustments can take, which can lead to employed disabled women not being fully supported in their work or leaving the workforce entirely.

Delivered by over 1.5 million people<sup>9</sup>, social care services are a lifeline for many disabled people. The social care sector is one that predominantly employs women – 82% of the social care workforce in England identifies as female.<sup>10</sup> Furthermore, within social care occupations, the Labour Force identified 22% of workers as disabled according to the Disability Discrimination Act 1995 definition. However, the adult social care workforce estimate shows a lower prevalence of disability among workers at 2%.<sup>11</sup>

Among the VODG members engaged in our discussions on this issue, many reported a workforce comprised mainly of older women, often with caring responsibilities at home and due to their age profile, at higher risk of certain health conditions. Menopause was often cited as a health condition that despite its prevalence is seen as a taboo subject, one that is little discussed, and one that women receive little to no support for in the workplace.

Whilst VODG believes that the government's workforce planning for social care needs to address expected demand for care and ensure a sufficient number of trained and skilled staff, it also needs to address how to create a rewarding and fulfilling sector in which to work. There must be a strategic focus on building healthy working environments that support women to recognise and discuss women's health issues, and to create guidance for employers on how to support women when those conditions impact upon participation at work.

Further to this, is the link between poverty and health. Social care staff across the country, who are also pre-dominantly women, are not paid at a level that enables them to live well. This undeniably can impact upon a woman's mental and physical health and wellbeing and can contribute to in-work poverty. The Joseph Rowntree Foundation has demonstrated that low-paid female underemployment is a big issue, and that that many women working part-time would work more hours if they had affordable and flexible childcare options available.<sup>12</sup> Wider progressive changes to

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<sup>9</sup> Skills for Care (2020) *The size and structure of the adult social care workforce in England, 2020*. [www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2020.pdf](http://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2020.pdf)

<sup>10</sup> *Ibid.*

<sup>11</sup> *Ibid.*

<sup>12</sup> Joseph Rowntree Foundation (2020) *What has driven the rise of in-work poverty*. [www.jrf.org.uk/report/what-has-driven-rise-work-poverty](http://www.jrf.org.uk/report/what-has-driven-rise-work-poverty)

the labour market could help to address long-standing structural inequalities within the social care labour market and improve recruitment and retention.

Social care is a labour-intensive sector, and the workforce should be recognised for the essential work they carry out. Indeed, given the impact care staff and the services they provide have on the lives of disabled people, the government should actively seek out solutions that lift disability services out of the low pay sector. Any government workforce strategy for social care must also include policy recommendations that will see fair pay settlements for social care staff introduced.

***Recommendation: Government's Workforce Strategy for social care, and future reform, includes specific policies and recommendations for creating healthy working environments and include guidance women-specific health issues.***

***Recommendation: Lift disability services out of the low pay sector and ensure that services for disabled people are funded well above the national minimum wage.***

## **7. Understanding and responding to the impacts of COVID-19 on women's health**

COVID-19 has shone a bright spotlight on many of the challenges faced by women, disabled and non-disabled, even before the onset of the pandemic but which have been further exacerbated over the last 12 months.

Women, and disabled women in particular, were already less likely to have health issues addressed and face challenges with accessing health and care services. As such, we can hypothesise that, as a result of the pandemic, there are a number of women currently living with undetected or underlying health conditions that could be addressed.

Isolation has been a significant challenge for many people during the pandemic, and many disabled women have been affected. Furthermore, for disabled women living in care settings there has been reduced family oversight and direct involvement from relatives in their healthcare during lockdown, which has not only increased isolation but also the risk of subtle changes in health and wellbeing going undetected.

Isolation has been further compounded by accessibility challenges since the onset of the pandemic. VODG members who support deaf women expressed concerns about health professionals wearing opaque facemasks making it impossible for deaf women who lip read. There is also the challenge presented by the move to telephone consultations, which may have resulted in fewer deaf women attending appointments and as a result, an increase in health issues going undetected or untreated.



## 8. Conclusion

While there exists policies and guidance aimed at ensuring that the provision of health and care is accessible to all, with disability not creating a barrier, it is clear that this aim is not being fully achieved.

It is vital that the Women's Health Strategy has at its core the voice of women, all women, and that it seeks to resolve and overturn historical inequities. To be truly equitable, the strategy needs to ensure disabled women are prioritised and that the impacts of COVID-19 on women are not overlooked.

The development of this strategy also needs to be a cross-government priority in which DHSC is working closely with colleagues across different government departments to address inequities that exist outside of health and care but that are intrinsically linked to health and care.

### Ends

For more information or to arrange a further a discussion with VODG or our members, please contact [research.policy@vodg.org.uk](mailto:research.policy@vodg.org.uk)