



# **Inquiry into Women's Pain**

## **Giving Voice to the Experiences and Needs of Women with Disabilities Living with Pain**

Submission to the Victorian Department of Health by Women with Disabilities Victoria

**31 July 2024**

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## Language Note

The remit of the Inquiry into Women’s Pain intends to cover: *“anyone who may experience similar health issues or gender-based discrepancies in care. This includes those assigned females at birth and anyone who identifies as a woman, though they may have a different sex at birth”*.<sup>1</sup> Our organisational submission may reflect the overlapping experiences of marginalisation experienced by cisgendered women as well as trans, non-binary, and gender diverse people. However, the experiences of trans and non-binary people warrant specific and direct exploration, particularly as they intersect with the health and medical system. We recognise limitations in aggregating our submission to the broader level of gender-marginalised people (people who do not identify as cisgender men). Instead, WDV aim to work in coalition with, rather than replicate the core work of organisations who represent and advocate for LGBTIQ+ people with disabilities.

This submission also uses ‘person first’ language (women with disabilities). We acknowledge people describe their experience of disability in different ways, and for many people, ‘identity first’ language is a source of pride and resistance.

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<sup>1</sup> Department of Health, Victoria, Australia. (2024, May 13). *Inquiry into women’s pain submissions – A note on language used*. <https://www.health.vic.gov.au/public-health/inquiry-into-womens-pain-submissions>

## Acknowledgment of Country

Women with Disabilities Victoria (WDV) respectfully acknowledges Aboriginal people as the Traditional Custodians of the lands and waters on which we work, rest, and continue to benefit from. We pay our respects to the Elders, past and present, of Aboriginal and Torres Strait Islander Communities across Victoria and acknowledge that their continued strength and resilience is built upon more than 60,000 years of history. The WDV community is committed to honouring the unique cultural and spiritual relationship Aboriginal and Torres Strait Islander peoples have with the land and waters, and their rich contribution to society.

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## About the Authors

**Women with Disabilities Victoria (WDV)** is a not-for-profit Disabled People's Organisation (DPO) representing women with disabilities in Victoria. The organisation is operated *by* and *for* women and non-binary people with varied disability experiences. WDV has a diverse membership of people from different backgrounds. Women with disabilities face intersecting forms of structural gender and disability discrimination. WDV actively advocates for our rights to safety and respect, with particular emphasis on disability policy, health services, violence prevention, workforce development, and leadership. WDV envisions a world where all women are respected and can fully experience life.

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## Executive Summary

Women with Disabilities Victoria (WDV) welcomes the Victorian State Government's inquiry into women's pain. For many women with disabilities across the state, pain is reported as a significant part of our everyday lives and can contribute to and exacerbate our experiences of disability. However, our experiences of pain are often dismissed as an inevitable part of our lives.

WDV advocates for changes to the way pain treatment is designed, delivered, and evaluated. We advocate for system-wide changes to health and disability policy and the valuing of the perspectives of women with disabilities through the centralisation of lived experience. The gendered and ableist barriers to treating pain must be addressed by this inquiry. To achieve this, WDV recommends more inclusive, accessible, and co-designed healthcare, and clearer linkage to NDIS provision, research, and education across the state. These changes will transform the lives of women with disabilities living with pain.

**Recommendation 1:** Invest in programs designed and delivered by women with disabilities to address ableism, bias, and medical misogyny in healthcare.

**Recommendation 2:** Co-design disability-inclusive, gender-responsive content with women with disabilities to educate medical and allied health professionals.

**Recommendation 3:** Consult with disability and gender-based advocacy organisations to bridge the gap between state healthcare and NDIS supports.

**Recommendation 4:** Resource advocacy organisations to address gender inequalities and ableism to increase participation of women with disabilities in all aspects of community life.

**Recommendation 5:** Conduct disability-led research to address barriers in pain recognition and treatment for women with disabilities.

### Terms of Reference Addressed:

- Identify the barriers and enablers when accessing care, treatment, and services for pain.
- Describe the impact of the current service delivery system on care for pain.
- Identify opportunities to improve the care, treatment, and services for pain.
- Consider appropriate models of care, service delivery frameworks, workforce skill mix, and other areas requiring change.
- Provide an opportunity for girls and women from across our community to share their experiences of pain and pain management in their own words, and for these experiences to be heard (see in particular Appendix 1).

## Background

For women with disabilities, seeking treatment for pain is shaped by gaps in the service and policy environment, sexist and ableist structures and attitudes pervading treatment systems, and the social systems in which women with disabilities live.

Women with disabilities, like women in general, often feel ignored when seeking help for their pain. Clinical research tends to focus on the experiences of cisgendered men and overlooks the specific conditions and gendered experiences of pain in women.<sup>2</sup> Women seeking pain treatment are frequently disbelieved,<sup>3</sup> offered limited treatment options, and have their pain attributed to psychological factors. As a result, their trust in healthcare providers becomes eroded.<sup>4</sup>

The patterned dismissal of women's pain is gendered. However, women with disabilities also experience the compounding effects of medical misogyny and ableism. Women with disabilities experience diagnostic overshadowing, whereby their symptoms are assumed to be part of their primary disability. Consequently, little investigation is made into other potential causes. Such neglect heightens women's risk of untreated/ undiagnosed health issues or illness.<sup>5</sup>

The combined impacts of pain, disability, and gender contribute to women's social isolation, reduced economic participation, and barriers to the fulfillment of social and community roles. These effects are mutually reinforcing. Women with disabilities living with pain are even more likely to have low incomes due to the combined effects of health-related costs, inflexible workplace practices, employer attitudes, and reduced health-related capacity to work. Lower income in turn affects economic and social participation, leading to greater isolation. This isolation is reinforced by prevalent community misunderstanding and lack of recognition of the multi-faceted impacts of pain. These factors, combined with reduced ability to engage in recreation, family, social, intimate, and community activities, further entrench women's isolation. This multifaceted isolation can increase psychological distress and exacerbate pain.

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<sup>2</sup> Samulowitz, A., et al. (2018). "Brave men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms Towards Patients with Chronic Pain. *Pain Research & Management*, 2018, 6358624.

<sup>3</sup> Campbell, K. A., et al. (2022). Women's Experiences of Navigating Chronic Pain Within The Context Of Living With An Episodic Disability. *Women's Health*, 18, 17455057221103994.; Women's Health Victoria. (2016). *Women and pain*. Women's Health Victoria, Melbourne. (Clearinghouse Connector; Sep 2016). <https://whv.org.au/>; Merone, L., et al. (2022). I just want to feel safe going to a doctor: Experiences of female patients with chronic conditions in Australia. *Women's Health Reports*, 3(1), 1016-1028. <https://doi.org/10.1089/whr.2022.0052>

<sup>4</sup> Gendered Pain: A Call for Recognition and Health Equity. (2024). *EClinicalMedicine*, 69, 102558.

<sup>5</sup> Howe, K. (2004, May 28). Lack of data means lack of action: A clinical examination of access to health services for women with disabilities. Women With Disabilities Australia Presentation to the HREOC Forum: "Access to Health Services for People with Disabilities." [https://humanrights.gov.au/sites/default/files/content/disability\\_rights/health/wwda.doc](https://humanrights.gov.au/sites/default/files/content/disability_rights/health/wwda.doc).

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### WDV Member Insight

*“[My] pain is very real. I don't think health providers realise that it takes a huge amount of energy for me to attend an appointment, and I would not be there talking about pain if it was not a significant problem for me. Telling me that it is a part of my conditions is not helpful and does not provide me with management strategies.”*

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Treatment and support for pain is grounded in the right to health care, a right recognised within various international instruments.<sup>6</sup> Despite this right to health care, women with disabilities continue to experience multiple and intersecting disadvantages and barriers when accessing support and treatment services for pain. WDV's submission highlights the causes of pain inequality and proposes solutions based on the experiences and recommendations of women with disabilities living with pain.

Appendix 1 of this submission contains direct statements of women with disabilities describing their experiences of pain, barriers to accessing support and treatment, their experiences of stigma, invisibility and bias, and their recommendations for systemic change. Evidence from our members was gathered by means of a survey sent to our members who had expressed an interest in participating in this inquiry. Our member survey highlights the voices of women with disabilities living with pain in alignment with the terms of reference for this inquiry. Their statements are supported by research evidence which is explored below.

## 1. Co-Design of Training and Programs

### **Pain programs, supports, and practitioner training must be co-designed by women with disabilities**

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<sup>6</sup> See for example, International Covenant on Economic Social and Cultural Rights (ICESCR); Articles 23(1C) and 25 Convention on the Rights of Persons with Disabilities (CRPD); Australian Commission on Safety and Quality in Health Care. (2019). *Australian Charter of Healthcare Rights*. <https://www.safetyandquality.gov.au/sites/default/files/2019-06/Charter%20of%20Healthcare%20Rights%20A4%20poster%20ACCESSIBLE%20pdf.pdf>; Australian Commission on Safety and Quality in Health Care. (2010). *Australian safety and quality framework for health care*. <https://www.safetyandquality.gov.au/sites/default/files/migrated/ASQFHC-Guide-Policymakers.pdf>; Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions*. <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>; Australian Government Department of Health and Aged Care. (2023). *National strategy for health practitioner pain management*.

While women with disabilities are experts in their own health, their voices are regularly dismissed by medical practitioners.<sup>7</sup> This highlights the need for a paradigm shift in healthcare delivery and pain treatment. WDV advocates for co-designing<sup>8</sup> treatment models with women with disabilities to enhance the effectiveness of care.<sup>9</sup>

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### **WDV Member Insight**

*“I have struggled with being believed, receiving the medical support needed, and often I do not receive Medicare subsidies for my pain treatment - the pain treatment offered is insufficient management for my condition. I feel stuck despite having a range of information available. I feel overinformed and undersupported.”*

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Co-design ensures that the specific experiences of women with disabilities living with pain are integrated into training for health professionals and the design of care models from the outset. This approach improves service accessibility, as the needs of women with disabilities are embedded within the design process.

Critically, co-design can also result in attitudinal changes within medical and support staff. This can positively impact pain treatment, as practitioners are better able to consider the aspirations of women with disabilities, recognise the gendered aspects of pain, value women with disabilities as experts and equal partners in their treatment, and be more open to their experiences and needs.

WDV maintains that securing high-quality, person-centred care and pain treatment in Victoria will require significant revision, monitoring, and evaluation of present policy frameworks through partnerships with women with disabilities and their organisations. It will also require investment in co-design programs and the incorporation of lived experience knowledge within workforces and service delivery systems.

Sustained investment would resource the development and monitoring of gender and disability indicators by which pain treatment models and delivery mechanisms within the wider health system can be co-designed, measured, and improved. The input of lived experience into monitoring and evaluation will ensure that existing health service delivery and research frameworks capture

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<sup>7</sup> Women with Disabilities Victoria. (2023). *Experts in our health project phase 1 evaluation report*. <https://www.wdv.org.au/wp-content/uploads/2023/09/WDV-Experts-in-Our-Health-Phase-1-Evaluation-Report-Aug2023.pdf>

<sup>8</sup> For a step-by-step guide in accessible and inclusive co-design practices see Women with Disabilities Victoria. (2022). *Inclusive co-design in practice*. <https://www.wdv.org.au/wp-content/uploads/2023/03/WDV-ICD-Poster-A4-1.pdf>

<sup>9</sup> As suggested in the National Strategy for Health Practitioner Pain Management. Australian Government Department of Health and Aged Care, 2023, p15.

and build on learning from women's lived experience of pain treatment such that:

- Gender and disability bias in pain research and service delivery are recognised, optimal performance indicators of gender responsive pain treatment models are developed, and success measured.
- Co-designed, delivered, and reviewed models of care for treating women with disabilities experiencing pain are contextualised within women's social environments and tailored to individuals.
- Specific outcome measures relating to the health of women with disabilities in relation to pain and its treatment can be tracked to monitor long-term improvement in wellbeing, based on disability and gender specific indicators.

Such measures align well with recommendations of the Disability Royal Commission into Violence, Neglect and Abuse of People with Disabilities (DRC) and the National Strategy for Health Practitioner Pain Management. Specifically, our suggestions are in alignment with recommendations that: existing national healthcare standards and frameworks be revised to include specific provisions for disability access; barriers to health access be reduced; and workforces and systems are made adaptable to the specific needs of people with disabilities.<sup>10</sup>

Further, current health service standards promote the importance of clinical education and ongoing professional development for building workforce capability. WDV believes that the only way to ensure effective delivery of disability and gender transformative health and disability support for women experiencing pain is by adopting best-practice co-design in clinical education and ongoing professional development.

The co-design of education for medical and allied health professionals must be consumer led, in partnership with educational institutions and other training bodies. The valuing of lived experience is best demonstrated by a commitment to implementation of co-design and co-creation of educational and professional learning curricula, with lived experience participants appropriately remunerated, and their perspectives centralised.

Women with disabilities living with pain engage with a variety of health and disability professionals, from primary care and allied health clinicians to disability service providers. WDV recommends that clinical and professional development include:

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<sup>10</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2023). *Final report - executive summary, our vision for an inclusive Australia and recommendations*. Commonwealth of Australia. <https://disability.royalcommission.gov.au/system/files/202311/Final%20report%20%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.docx> p.88-89.; National Strategy for Health Practitioner Pain Management. *Australian Government Department of Health and Aged Care, 2023.*



- Human rights models of disability, and their applicability to pain-related clinical services.
- Gender and disability analysis of barriers to health in general and pain treatment in particular, and approaches for reducing these barriers.
- Gender affirming models of treatment and service delivery that deliberately challenge disability and gender bias and hierarchies in medical care and disability service provision.
- Recognition of the prevalence of violence against women with disabilities, its relationship to ongoing pain, and application of preventative frameworks such as Changing the Landscape.<sup>11</sup>

WDV promotes the value of organisations of women with disabilities as holders of the expertise necessary to support the co-design of relevant clinical and professional educational programs. These organisations are well-versed in the value base, knowledge, and lived experience input needed to co-design such programs. With appropriate funding, as experts in co-design research, training, program development, and delivery, WDV are well-positioned to support the government in developing and implementing a co-designed approach to pain treatment in Victoria.

**Recommendation 1:** Invest in programs designed and delivered by women with disabilities. This will address ableism, bias, and medical misogyny in the provision of healthcare.

**Recommendation 2:** It is crucial that content regarding disability and intersectional practice is co-designed by women with disabilities and embedded within medical and allied health education and professional development. In this way, women with disabilities will receive treatment which affirms their gender and disability, and links them to appropriate disability and health services.

## 2. Consultation with Disability and Gender-Based Systemic Advocacy Organisations

**Consultation with and resourcing of advocacy organisations is needed to address underlying structural inequalities and ableism.**

Systemic advocacy organisations need to be resourced to address the underlying structural gender inequalities and ableism in policies, institutional processes, and community attitudes and behaviours. It is these attitudes and inequities that are challenged by systemic advocacy organisations like WDV.

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<sup>11</sup> *Changing the landscape*. (2022). *Our Watch*. <https://www.ourwatch.org.au/change-the-story/changing-the-landscape>

Challenging these barriers will increase the participation of women with disabilities in all aspects of community life.

While the experience of pain is individual to each woman with disability, it is shaped by common structural issues. These structural issues include gender and disability marginalisation, and ableism and gender bias in clinical, service, and policy systems. They also include the high prevalence of violence against women with disabilities and its associated trauma, perpetrated by individuals and service systems. Ongoing or episodic pain is also impacted by these structural inequalities. Thus, addressing women's pain needs to incorporate gender and disability transformative approaches to reduce the barriers of gender discrimination and ableism in society.

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#### **WDV Member Insight**

*“Disabled women and NBfolk, also experience pain, just like non disabled people. And ... our pain may be unrelated to our disability. So disabled people deserve investigation like everyone. I am sick of my disabled female and NB friends dying from late-[stage] cancer, because their pain was not believed and not investigated. In short, health professionals need a crash course in Ableism (and sexism and racism etc ) to show the inherent disabled discrimination in the health system.”*

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Women disproportionately fall through support system gaps. Primary and chronic health care systems do not provide for access to ongoing daily living supports. This leaves women with disabilities living with painful conditions with limited access to funded supports to maintain quality of life and fully participate in family and community.<sup>12</sup> It is often the case that women with disabilities are ineligible for support under the NDIS.<sup>13</sup> This is despite minimal differences in disability rates between male and female identifying people.<sup>14</sup> Factors contributing to this disparity include:

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<sup>12</sup> Piantedosi, D., Molnar, L., Panisset, M., & Wilding, R. (2024). There is overwhelming gender bias in the NDIS – and the review doesn't address it. *The Conversation*. <https://theconversation.com/there-is-overwhelming-gender-bias-in-the-ndis-and-the-review-doesnt-address-it-220042>

<sup>13</sup> Piantedosi, D., Molnar, L., Panisset, M., & Wilding, R. (2024). There is overwhelming gender bias in the NDIS – and the review doesn't address it. *The Conversation*. <https://theconversation.com/there-is-overwhelming-gender-bias-in-the-ndis-and-the-review-doesnt-address-it-220042>

<sup>14</sup> Yates, S., et al. (2021). Women's experiences of accessing individualized disability supports: Gender inequality and Australia's national disability insurance scheme. *International Journal for Equity in Health*, 20, 1-14.

- Greater prevalence of chronic conditions resulting in pain.<sup>15</sup> These conditions are less likely to meet the schemes eligibility classifications of disability.<sup>16</sup>
- A hesitancy in shouldering the administrative burden required for application and participation given the lack of certainty of outcomes.
- Gendered role expectations leading women to prioritise care provision for others rather than themselves.

These factors result in inequitable access to daily living supports for women with disabilities, many of whom live with episodic or ongoing pain.<sup>17</sup>

WDV recommends that these service gaps and outcomes be monitored through data collection, research, and advocacy with a view to system reform. We recognise the shifting landscape of NDIS provision, given the recent NDIS review which proposes an expanded role for the states in delivering foundational disability supports. We also recognise changing health system delivery contexts due to demographic and technological changes, and constrained fiscal environments. However, WDV is concerned that, unless research, policy, and advocacy consideration is prioritised, women with disabilities living with pain will continue to fall through service gaps, potentially exacerbating the impacts of pain and increasing social and economic marginalisation.<sup>18</sup>

To counteract this, WDV recommends urgent investment in organisations able to deliver lived experience representation in health and disability policy arenas affecting women with disabilities. As a historically deprioritised group, this will ensure that the voices of women and their needs and rights remain visible, particularly within ongoing disability system reform.

WDV supports the implementation and review of disability and gender frameworks such as the Victorian State Disability Plan, the Commonwealth Disability Strategy, the recommendations of the DRC, and state and Commonwealth gender equality and violence prevention plans. Peak body organisations for women with disabilities have a crucial role to play in advancing rights and providing policy makers a direct link to affected communities through lived experience perspectives. Working in partnership with representative organisations like WDV will ensure lived experience can meaningfully inform messaging and campaigns within the disability community

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<sup>15</sup> Pain Australia. (2019). Enabling people with persistent and chronic pain: The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. *Pain Australia*. <https://www.painaustralia.org.au/media/media-document/blog-1/blog-2020/blog-2019/enabling-people-with-persistent-and-chronic-pain-the-royal-commission-into-viole>

<sup>16</sup> Pain Australia. (2019). Enabling people with persistent and chronic pain: The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. *Pain Australia*. <https://www.painaustralia.org.au/media/media-document/blog-1/blog-2020/blog-2019/enabling-people-with-persistent-and-chronic-pain-the-royal-commission-into-viole>; "Women Make Up Half the Disability Population but Just Over a Third of NDIS Recipients." *The Conversation*, 2021, <https://theconversation.com/women-make-up-half-the-disability-population-but-just-over-a-third-of-ndis-recipients-173747>.

<sup>17</sup> "Women Make Up Half the Disability Population but Just Over a Third of NDIS Recipients." *The Conversation*, 2021, <https://theconversation.com/women-make-up-half-the-disability-population-but-just-over-a-third-of-ndis-recipients-173747>.

<sup>18</sup> Yates, S., et al. (2021). Women's experiences of accessing individualized disability supports: Gender inequality and Australia's national disability insurance scheme. *International Journal for Equity in Health*, 20, 1-14.

as well as broader systemic advocacy activities, policy reviews, and continuous improvement processes.

WDV recommends that commitment be made to investment in monitoring and review of policy frameworks pertaining to gender and disability, and the appropriate resourcing of women's disability organisations to bring the specific perspective of women with disabilities to this work.

**Recommendation 3:** Consult with disability and gender-based advocacy organisations to bridge the gap between state healthcare and NDIS supports. In this way, the gap in women's access to NDIS services will be reduced.

**Recommendation 4:** Resource systemic advocacy organisations to address structural gender inequalities and ableism. This will increase the participation of women with disabilities in all aspects of community life.

### 3. Disability-Led Research

**Research led by community-based disability organisations is needed to understand and address barriers to pain treatment.**

Research on the intersections of pain, gender, and disability is vital for generating solutions to the poor outcomes and barriers to treatment that women with disabilities receive. Research must centre women with disabilities as experts and leaders to be truly responsive to the needs of women with disabilities.

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#### ***WDV Member Insight***

*“We are the experts in living with our pain!! That we already do so much to manage our pain, so don't dismiss our efforts. Your role is to build on my current pain [management], not dismantle it.”*

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Several research frameworks and guidance tools exist for best practice research with people with disabilities. For example, the Disability Innovation Institute suggests that best practice disability research is guided by principles of power-sharing, diversity, accessibility, reciprocity, and transparency.<sup>19</sup>

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<sup>19</sup> Strnadová, I., et al. (2020). Doing research inclusively: Guidelines for co-producing research with people with disability. *DIU UNSWSydney*. <http://disabilityinnovation.unsw.edu.au/sites/default/files/documents/DIU%20Doing%20Research%20Inclusively->

When considering research into treatment and support services for women with disabilities living with pain, WDV believes that the application of these principles will promote shared power and non-hierarchical practices among research stakeholders, centralising women with disabilities as experts. While clinical and academic involvement in research is important, it is only women with disabilities and their representative organisations who hold lived expertise of the impacts of pain. Therefore, platforming women with disabilities to lead this work will ensure that the effects of treatment and service delivery models are properly understood.

By prioritising a disability-led research agenda in women's pain, research becomes focused on themes of identifiable interest to women with disabilities experiencing pain and associated treatment systems. The approach also better ensures that research does not perpetuate bias and false assumptions regarding the drivers and intersections of pain, gender, and disability. Further, this approach will also ensure that women with disabilities benefit from research through appropriate remuneration of their expertise and strengthened capacity as co-researchers. Additionally, the approach can better ensure accessibility in research design, methodology, implementation, and dissemination of findings to ensure the full participation of women with disabilities.

Best practice requires an assurance that disability-led research related to pain and women with disabilities directly informs evolving health and disability policy in Victoria. Women with disabilities and their representative organisations are well placed to link research to current and future policy needs through ongoing input of women with disabilities. Working in partnership, disability organisations like WDV can promote the dissemination of research findings in ways that are accessible to both women with disabilities affected by pain and the service providers/policy makers addressing their needs. In this way, a clear link is created between all research stakeholders, resulting in improved practice.

Finally, supporting disability-led research can also promote lived experience as a valuable source of knowledge, informing research priorities around women's pain. It can also promote the research capacity of women with disabilities themselves through remunerated peer-researcher roles. The representative organisations of women with disabilities have the capacity to provide supportive structures for lived experience. Partnership approaches led by these organisations are best equipped to communicate best practice around women's pain, and to share research outputs and findings with key policy makers, health service providers, and women with disabilities in a variety of accessible formats.

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[Guidelines%20%2817%20pages%29.pdf](#); see also, National Disability Research Partnership. (2020). *Principles*. <https://www.ndrp.org.au/principles>.

**Recommendation 5:** Conduct community led research to address the barriers to the recognition and treatment of pain experienced by women with disabilities. Such disability-led research will amplify the voices and experiences of women and non-binary people with disabilities.

## Appendix 1: Voices of Women with Disabilities

### Purpose and Structure

This appendix supplements the submission made by WDV to the Inquiry into Women's Pain, presenting insights from members of our organisation derived from their lived experience of the intersection of gender, pain, and disability. In support of the terms of reference for this inquiry, this material will provide a snapshot of experiences from a sample of our members, across a range of ages, backgrounds, and geographic locations.

Comments and responses from women with disabilities are presented to illustrate the experiences of women and non-binary people with disabilities living with pain, and to present their suggestions for system improvement firsthand.

### Methods

#### Data Collection

An online survey was developed based on this Inquiry's Terms of Reference, containing a mixture of demographic, multiple choice, and open-ended questions to elicit both quantitative and qualitative responses. The survey was prepared and administered via the Survey Monkey platform, which also facilitated data collation. The survey was designed based on the Web Content Accessibility Guidelines 2.1, and was user tested for accessibility with screen reading software.

#### Participant Recruitment

Convenience sampling was utilised to recruit survey participants, who had expressed interest in being contacted about this Inquiry through a voluntary question in WDV's annual member survey in March 2024. 23 members chose to receive the Inquiry survey via email. They were provided with an overview of the Inquiry, a link to its website, a list of the Inquiry's Terms of Reference, and information on the use and storage of participants' survey data. Participants were informed that completing the survey was voluntary and were asked to consent to the use of their data and quotations in WDV's submission to the Inquiry. They were also offered assistance to complete the survey verbally if desired. 9 survey responses were received, all of which consented to the use of their data in Inquiry. These responses are included in this appendix, with quotations presented as provided by participants.

#### Limitations

The goal of the survey was to capture qualitative responses to contextualise our recommendations and the evidence base presented. Due to time and funding constraints, we could not survey across the breadth of the disability community. As such, these findings cannot be interpreted as representative of *all* women with

disabilities. We recommend future surveys include purposive recruitment strategies and collect expanded demographic data in an ethical manner to better account for the experiences of women and nonbinary people with disabilities.

## Respondents' Demographic Profile

A total of 9 participants completed the survey. Among them, 2 participants (22.22%) were aged 25-34, 2 participants (22.22%) were aged 35-44, 2 participants (22.22%) were aged 45-54, and 3 participants (33.33%) were aged 55-64. 4 respondents (44.44%) live in regional Victoria, while 5 respondents (55.56%) reside in metropolitan Victoria.

## Member Insights

### 1. Opinions of Pain Treatment and Support Services

#### Question 4

Respondents were asked to choose from a list of factors that they had experienced as helpful when accessing treatment for pain. The factors regarded as most helpful presented in ranking order were:

- **I have been listened to and believed by health professionals when describing my pain.** 7 respondents (77.78%).
- **I can make decisions about my treatment options in partnership with my health service providers.** 6 respondents (66.67%).
- **Information about services, supports, and treatment options are available in formats accessible to me.** 5 respondents (55.56%).
- **Costs for my treatment are subsidised by Medicare.** 5 respondents (55.56%).
- **I am given treatment options that meet my individual needs.** 5 respondents (55.56%).
- **The services and supports I need to treat my pain are close to where I live.** 4 respondents (44.44%).
- **The facilities where services and treatment are provided meet my accessibility needs.** 4 respondents (44.44%).

2 respondents commented:

*"I have struggled with being believed, receiving the medical support needed, and often I do not receive Medicare subsidies for my pain treatment - the pain treatment offered is insufficient management for my condition. I feel stuck despite having a range of information available. I feel overinformed and undersupported."*

*"Out of pocket costs are so high that I have forgone treatment to save money."*

## Question 5

When asked about barriers experienced when accessing support in question 5 (services and treatment for pain), participants provided the following responses in order of prevalence:

- **Costs for my treatment are not subsidised by Medicare.** 9 respondents (100%).
- **I have not been listened to or believe by health professionals when describing my pain.** 8 respondents (88.89%).
- **The treatment options I am given do not meet my individual needs.** 6 respondents (66.67%).
- **I am not involved in decisions about my treatment options.** 3 respondents (33.33%).
- **The services and supports I need to treat my pain are far from where I live.** 3 respondents (33.33%).
- **The facilities where services and treatment are provided do not meet my accessibility needs.** 3 respondents (33.33%).
- **Information about services, supports, and treatment options are not available in formats accessible to me.** 2 respondents (22.22%).

1 respondent commented:

*"Because I present as high functioning, my condition has worsened severely and the pain management options available to others are not offered to me. I have sucked it up and gotten on with a level of pain and discomfort that has increased the severity of other conditions, and made dealing with my other disabilities more difficult."*

## Question 6

In question 6, Participants were asked to select from a list of health and medical professionals to whom they had spoken about their pain. Responses were as follows:

- **GP.** 9 responses (100%).
- **Physiotherapist.** 6 responses (66.67%).
- **Mental health professional (counsellor, social worker, psychologist etc.).** 5 respondents (55.56%).
- **Pain specialist.** 5 responses (55.56%).
- **Occupational therapist.** 3 respondents (33.33%).
- **Other (dietician, exercise physiologist, osteopath, and neurologist).** 3 respondents (33.33%).



## Question 7

When asked about their overall satisfaction with the support, services, and treatment they received for pain in question 7, only 1 respondent (11.11%) reported feeling very satisfied, a further respondent reported feeling satisfied. 4 respondents (44.44%) reported feeling dissatisfied, with a further 3 (33.33%) reported feeling very dissatisfied.

## 2. Suggested Improvements to treatment, care and services for women and non-binary people with disabilities living with Pain

### Question 8

In question 8, respondents were asked to supply suggestions for improvements to services for women and non-binary people with disabilities accessing treatment for pain, and provided the following responses:

"Believe us! don't just refer us to psychology, as if our pain is not real... reduce the long wait lists for pain programs... reduce the overwhelming bureaucracy... make hydrotherapy more accessible, both cost and more warm water pools."

"Services in regional Victoria. I should not need to travel to Melbourne for a pain management clinic. The travel caused further pain."

"Actually offer us more than paracetamol or ibuprofen. Having a disability does not mean I'm a drug seeker nor making it up or imagining it. I have daily dislocations, skin tears, arthritis, muscular pain, etc. Actually believe me and don't talk down to me."

"Improved communication and understanding from medical professionals. Empowering me with input into pain care and support that considers my whole life - as a mum, partner, employee and much more."

"Greater recognition that pain is very real. I don't think health providers realise that it takes a huge amount of energy for me to attend an appointment, and I would not be there talking about pain if it was not a significant problem for me. Telling me that it is a part of my conditions is not helpful and does not provide me with management strategies."

"1. To not be immediately dismissed when you mention pain.

2. Medical establishment to not blame patients for being stressed or emotionally unregulated.

3. Medical establishment to acknowledge and respect that patients know their bodies and know when something is inherently wrong.

4. For patients to learn the "language" necessary to relay information which helps having it heard.
5. Particularly when a patient experiences a diagnostic odyssey, tears do not mean instability but a response to the journey.
6. Medical gaslighting and misogyny is very real - education at the beginning of career is paramount to systemic bias."

"I understand that there is an understandable fear of how addictive some pain management medications are. So many medical practitioners are reticent to prescribe a sufficient amount unless you have been in a car crash or are recovering from surgery or something. There needs to be a balance where a doctor can understand how to trust a patient's capacity to engage with them and speak about their pain. As a woman, the amount of pain I feel I have to 'put up with' could actually put my life in danger. I can see how some people could end up misusing other over the counter, or other recreational drugs to self-medicate and cope through the pain that they might otherwise get support with. My experience of pain has used against me in my previous relationships and to gaslight me, and I think better understandings about how to provide treatment for women and nonbinary people who experience chronic pain can also mean that this is less likely to happen."

"I just want to have access to affordable healthcare and for my pain to be believed."

"I am unsure if this is possible, but lowering out of pocket expenses would be helpful. I do not qualify for a Health Care card, pensioners card or any other subsidies. Thus, I am foregoing treatment to save money. I can buy food, pay my mortgage payments & pay bills, but a procedure that could reduce my pain is out of reach, as I do not qualify for any financial assistance."

## Question 9

Question 9 asked participants to nominate their top 3 priorities to improve the experiences of women and non-binary people with disabilities living with pain conditions from a list of options. Their priorities are:

- **Disability led research on barriers to the recognition and treatment of women's pain.** 8 respondents (88.89%).
- **Co-designed health services by women and nonbinary people living with pain conditions.** 7 respondents (77.78%).
- **Improved coordination between the health system, NDIS and other disability support systems.** 6 respondents (66.67%).
- **Training of health professionals in gender and disability inclusive practice.** 5 respondents (55.56%).

## Question 10

In question 10, when asked to identify the attitudes, beliefs, and values participants wished health professionals treating their pain to demonstrate in interactions with them, participants made the following comments:

"That we are the experts in living with our pain!! That we already do so much to manage our pain, so don't dismiss our efforts. Your role is to build on my current pain mx, not dismantle it."

"I'm on equal footing and not seen as a nuisance. A doctor once told me that he would not treat me because I'm disabled and he hoped withholding treatment would help me die faster ('end my suffering'). So, yeah, don't do that. My life is more limited by not being able to receive the treatment I need. See my life as worth being lived. See that I want to do more with my life and can with pain relief or seeing relevant specialists. GPs have often refused to write a referral, even.."

"Empathy and understanding."

"An attitude that recognizes my expertise with my own body. They may have a theoretical understanding of conditions, but cannot know my experience or the severity of symptoms that I am feeling.... I would also like to see a greater collaborative approach - for example, a pain specialist recommending four procedures that are inappropriate due to my co-conditions and not offering any non-invasive suggestions for pain management is a waste of everybody's time."

"Respect, honesty (if they don't know what they are dealing with, say it) and curiosity to explore beyond the standard theory of what seems to be a fad definition of pain.... Respect for individual care - we don't all come from the same mould."

"Please challenge medical misogyny. It increases health risks, worsens pain, and just makes life more shit.... Not everyone complaining about their pain is a drug user or at risk of addiction. Believe us. Look at our medical history, we're in pain! If a cis man with my conditions and history of injury came into your office, I doubt he would have the same challenges receiving treatment."

"To become more knowledgeable about pain that women experience and show some understanding and be professional in their response.."

"Compassion, empathy, knowledge of neurological pain (nerve pain, MS) & understanding."

## Question 11

Question 11 invited participants to comment on the skills and knowledge they believed professionals treating their pain should possess. Participants offered the following suggestions:

"So much, but one thing is that Disabled women and NBfolk, also experience pain, just like non disabled people. And that our pain may be unrelated to our disability. So disabled people deserve investigation like everyone. I am sick of my disabled female and NB friends dying from late dx cancer, because their pain was not believed and not investigated. In short, health professionals need a crash course in Ableism (and sexism and racism etc ) to show the inherent disabled discrimination in the health system."

"Spend more than 1 day Googling it. Chronic pain is very real. We're told to only seek medical information from peer reviewed sources, yet doctors have literally looked at Wikipedia in front of me on their computer. Do more research - from legit sources - into chronic pain and its impacts."

"New and emerging treatments, availability of medicinal cannabis and understanding that pain conditions fluctuate over time, what works one day may not the next. Pain care needs to respond at all stages."

"This is tricky, I would like to see GPs and specialists have a better understanding of chronic conditions that are more likely to impact women (such as ME/CFS, fibromyalgia, EDS) but I also acknowledge that it is impossible to have in depth knowledge of all conditions."

"Skills to not just dump you in the "it's all in your head" category. That is a cheap and easy response to symptoms that are not "usual". Training in understanding the emotional impact that patients can experience with pain. That emotions don't CAUSE pain but having a disease with high pain levels can be very distressing."

"This might be a policy or legislation gap but there was a significant change in my quality of life, productivity, and activity when paracetamol with codeine became a prescription only drug. I understand the reasoning here, but this has significantly reduced my wellbeing."

"I believe that a course in various areas that women experience pain in would be beneficial."

"Experience & interest in helping & supporting those with invisible disabilities, such as severe nerve pain. Background in some of the psychological struggles we go through on a daily basis."

## Question 12

Question 12 asked respondents to choose from a list of areas in which they believed further research was needed to better understand women's pain. Their choices are presented in order of popularity below:

- **Effects of chronic and fluctuating pain for women and nonbinary people with disabilities.** 8 respondents (88.89%).

- **The impact on women's pain on work, inclusion, wellbeing, and safety.** 8 respondents (88.89%).
- **Access to health services, treatment, and information by women and nonbinary people with disabilities.** 5 respondents (55.56%).
- **Menstrual pain and disability.** 5 responses (55.56%).

### Question 13

Question 13 invited participants to share additional comments regarding their experiences of pain and accessing treatment and support. Respondents commented:

"Yes. whilst I live with chronic pain, I have been conditioned to (and also strived) to make it invisible so that others are comfortable and that people don't further isolate me due their own fears. This includes health professionals. Sometimes I feel so conditioned to hide my pain, that it becomes very difficult to talk about it, leading to further disbelief.... catch 22."

"I moved to this district of Victoria 11.5 years. I had a good GP where I used to live but had to move far from there. It took me 10 years to find another GP who doesn't minimise me, writes referrals and believes me. It shouldn't take that bloody long. 10 years of my life gone, where I could have done more with my life if it weren't for chronic pain. I'll never get those years back. However, I'm back in chronic pain because the doctor moved - new doctor whom I swear takes several visits to organise things. Very slow."

"Fill your story telling box with examples of how the pain makes you feel. Ask practitioners who you trust to help fill that box with the language that will help you to be heard. E.g. today my scar feels like it has been injected by crushed up razor blades and that these are now circulating around in my blood. This week my pain was so bad, I could not raise my head from my pillow and I didn't shower for 4 days. Today I slept 18 hours and had to keep the lights off to manage my pain levels etc. Giving examples of how pain is impacting life can sometimes give practitioners who are willing to listen, some context to how bad it is."

"I think that this inquiry is incredibly important but I want change to happen yesterday."

"I am unsure if this is possible, but lowering out of pocket expenses would be helpful. I do not qualify for a Health Care card, pensioners card or any other subsidies. Thus, I am foregoing treatment to save money. I can buy food, pay my mortgage payments & pay bills, but a procedure that Could reduce my pain is out of reach, as I do not qualify for any financial assistance."