A report for the **Department of** Health's Women's **Health Taskforce** Improving the health outcomes and experiences of the healthcare system for marginalised women National Women's Council



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### **Context**

In September 2019, the Department of Health established the Women's Health Taskforce to improve women's health outcomes and experiences of healthcare. An initial desk-based evidence review, Women's Health in Ireland - Evidence Base for the development of the Women's Health Action Plan 2019" was produced to support the development of this policy work and this provided an overview of what is known about women in Ireland in terms of demographics, health and engagement with health services. Alongside this, the Department engaged a research consultancy MCCP to undertake a three-strand research project to better understand the lived experience of women of all ages in Ireland. This project included a social media analysis and a series of radical listening workshops and one-to-one interviews. All research undertaken for the Taskforce follows a radical listening approach, derived from the work of Professor Carol Gilligan and Professor Kenneth Tobin. Radical listening as a methodology highlights the importance of creating a non-judgemental and safe environment where participants are taken seriously as experts by experience and trust is established. The radical listening approach recognises the structural inequalities which can inhibit people having voice and input, and as such consideration is also given to what is left unsaid and why.

To complement this work, in June 2021, the National Women's Council (NWC) and Community Work Ireland (CWI) conducted a second series of radical listening workshops with particular groups of marginalised women who we know to have significant health needs, but who are at greater risk of having poor experience of services. These targeted workshops were organised to provide space to discuss the conditions needed to promote positive health and wellbeing, and to identify what the key enablers and barriers are for accessing high-quality and needs-based healthcare. This work was commissioned to support the development of the Women's Health Action Plan, an outcome of the work of the Women's Health Taskforce.

#### November 2021

See, Tobin, K. (2009) Tuning into others' voices: radical listening, learning from difference, and escaping oppression. *Cultural Studies of Science Education*. 4, 505–511; Carol Gilligan is University Professor at NYU and initiated their Radical Listening Project.

### **Executive Summary**

The radical listening workshops were designed to provide a platform for marginalised women to share their experiences of the Irish healthcare system in a safe and enabling environment. From the *Women's Health in Ireland* evidence review, we know that there are multiple groups of women in Ireland who have distinct healthcare needs but who face barriers to accessing good care. Many of these women are represented across multiple groups, and even within a group, each women's experience is unique and health needs and outcomes can differ.

To better understand the diversity of needs, four workshops took place over Zoom in June 2021 with a total of 50 women taking part from both urban and rural areas. Based on the evidence review and the ability of the National Women's Council and Community Work Ireland to recruit participants via organisations they were already connected with and trusted, the workshops took place with:

- Disabled Women
- Women of Minority Ethnicity
- Women Living in Socially and Economically Disadvantaged Communities
- Women Survivors of Violence and Abuse

Participation was based on self-identification with the theme of the workshop and a radical listening approach was deployed to ensure that women could share openly on their experiences of the healthcare system. Women raised a range of concerns, including, but not limited to, the lack of accessibility of certain health services, gaps in language and translation support, problems in accessing timely care of high quality, lack of join-up of services, the burden of navigation falling on the service user, and the adverse impact other aspects of social policy were having on their health and ability to access to care.

The research design also included asking participants what an enabling and inclusive health system would look like, and in response to this question, women offered recommendations as to what could be improved. The recommendations proposed by the women were supplemented by recommendations offered by NWC based on analysis of the concerns raised in each workshop.

The final report with recommendations was then reviewed by the participants as part of the ethics and quality assurance process and no revisions were asked for.

This methodology allowed for a robust analysis of marginalised women's health needs and resulted in recommendations which seek to put women's experiences at the heart of health policy. Although a diverse range of women took part in the workshop, four primary recommendations emerged from analysis of the discussions that took place. These are spotlighted below and provide the blueprint for moving to an inclusive, women-centred and feminist healthcare system that is grounded in the needs of women.

#### **Summary of NWC Recommendations:**

#### View women as equal partners

- Introduce gender-sensitivity and unconscious bias training, beginning in undergraduate curriculums and continuing across professional development. This should be co-designed with a diverse cohort of women, including those who are experts by experience on different health conditions.
- Ensure that training emphasises that clinical best-practice and shared decision-making go hand-in-hand and equips professionals with the skills and knowledge necessary to support meaningful service-user input.

### Champion community-based care and community development support

- Invest in local, accessible supports for health promotion and early intervention; including through additional funding for the Traveller Primary Healthcare Projects, community resource centres and local domestic abuse services.
- Improve GPs' knowledge of local support services to ensure more women are made aware of and connected to relevant services within their communities.
- Examine the viability of introducing peer-led primary health care for migrant communities and those living in socioeconomically disadvantaged areas, designed and implemented with women from these communities.
- Enhance pathways between community and specialist care to ensure that where additional support is needed, there is a smooth referral process.
- Explore feasibility of international models of good practice in primary care such as the UK's Identification and Referral to Improve Safety intervention to improve support for women subjected to domestic abuse and ensure access to timely and appropriate healthcare.

#### Promote accessibility and inclusion

- Champion universal design planning and ensure that all services are provided to disabled women as they would their able-bodied peers.
- Enhance access to interpretation and translation services for Irish Sign Language and foreign languages.
- Provide clear and accessible information on the care pathway in a variety of forms to enable service-user engagement.
- Improve diversity and representation across all tiers of the health
  and social care workforce and ensure that women from marginalised
  backgrounds can develop their careers and progress to senior levels.

#### Collaborate across Government

- Recognise that the common universal drivers of marginalisation, including poverty, deprivation, racism, gender-based violence, social exclusion, ableism, family hardships, and trauma are cross-Government issues.
- Identify areas of current social policy that have a particular adverse impact and proactively engage across Departments by adopting a 'health in all policies' approach.
- Use the forthcoming third National Strategy for Domestic, Sexual and Gender-based Violence to tackle the epidemic of violence against women by adopting a public health approach to abuse prevention. The Strategy should be clear that violence against women is preventable, and outline coordinated cross-departmental actions to address the risk factors that increase the likelihood that harm will occur.
- Develop a holistic and intersectional approach between the Department of Health and Department of Justice to protect the safety and mental and physical health of survivors of domestic abuse.

### Introduction

The primary literature review guiding this project was the *Women's Health in Ireland 2019* evidence review.<sup>2</sup> This review highlighted multiple groups of women who can have significant health needs but who face barriers to accessing an adequate standard of healthcare, including:

- Migrant women
- Traveller and Roma women
- Disabled women
- LGBTQI+ women
- Carers
- Socio-economically disadvantaged women
- Women who are homeless
- Women in prostitution
- Women with experience of the criminal justice system
- Women experiencing violence and abuse

In order to better understand the health inequalities between women, the review provides a brief overview of the evidence surrounding the particular health needs and experiences of each of the identified diverse groups, presenting each group as separate categories. It is important that this section is read in the context of the wider report. As the report alludes to, many women will be represented in multiple groups. Given the complexity of women's identities and experiences, and the fact that this is not an exhaustive list, we should be cautious about adopting a siloed approach when applying the research into practice.

Instead, we seek to connect back to the common structural drivers and social determinants of poor health experiences and outcomes which unite women across multiple groups, and in doing so are alert to the need for earlier and more timely support to promote health and wellbeing across the life course. For example, there is a robust body of research demonstrating that early experience of adversity is associated with significant physical and mental

Walsh, K. (2019) Women's Health in Ireland, Evidence Base for the development of the Women's Health Action Plan – see in particular sections 2.5-2.7 <a href="https://www.nwci.ie/images/uploads/Womens\_Health\_in\_Ireland\_-\_Evidence\_Base\_for\_the\_Development\_of\_the\_WHAP\_-\_2019.pdf">https://www.nwci.ie/images/uploads/Womens\_Health\_in\_Ireland\_-\_Evidence\_Base\_for\_the\_Development\_of\_the\_WHAP\_-\_2019.pdf</a>

health needs across the life course,<sup>3</sup> as well as greater risks of social exclusion and service need in adulthood.<sup>4</sup>

Across all of this work, we are clear that no group of women is internally homogenous given that no two experiences will be exactly the same, and even for those who do have similar experiences, health outcomes are not fixed or inevitable but rather shaped by our access to psychological and social protective factors, as well as differences in relationship to power and resources.

All of this is to say that when considering the experiences of marginalised women in health policy development, we are mindful of the complexities of identity and how these relate to health needs and experiences of the system. Ultimately, we adopt an intersectional approach that seeks to understand the multiple and overlapping sources of subordination and oppression that some women persistently face, rather than seeing them in terms of crude or static categories.

Given this, it is vital that we listen to women and ground our policy and practice in their lived experience from the outset. This involves acknowledging and seeking to address oppressive practices within the Irish healthcare system itself, as well as working to address the wider factors that can adversely impact health outcomes.

#### **Content Warning**

In the following report we share direct quotes from the women in their own words. The nature of the experiences discussed in this report are of a sensitive nature and may be distressing for some readers.

<sup>3</sup> See for example: Bellis MA, Hughes K, Ford K, Ramos Rodriguez G, Sethi D, Passmore J. (2019) Life course health consequences and associated annual costs of adverse childhood experiences across Europe and North America: a systematic review and meta-analysis. *Lancet Public Health*; Kalmakis, K. A., & Chandler, G. E. (2015). Health consequences of adverse childhood experiences: a systematic review. *Journal of the American Association of Nurse Practitioners*, 27(8); Norman and Byambaa et al (2012) The long-term health consequences of child physical abuse, emotional abuse, and neglect: a systematic review and meta-analysis, PLoS Medicine

<sup>4</sup> A Caspi, RM Houts, DW Belsky, et al. Childhood forecasting of a small segment of the population with large economic burden, (2016) *Nature Human Behaviour* 

<sup>5</sup> See for example, Allen, J., Balfour, B., Bell, R. & Marmot, M. (2014) Social determinants of mental health, *International Review of Psychiatry* 

<sup>6</sup> McCartney, G., Dickie, E., Escobar, O. & Collins, C (2020). Health inequalities, fundamental causes and power: towards the practice of good theory. *Sociology of Health & Illness*.

<sup>7</sup> Ann Denis (2008) Intersectional Analysis: A Contribution of Feminism to Sociology, International Sociology Review of Books Vol. 23 No. 5

## Research Objective and Methodology

Building on the evidence gathered to date, this project was concerned with two key questions:

- 1. What is the experience of the Irish healthcare system for diverse groups of marginalised women and what are the key barriers to accessing person-centred and appropriate care?
- 2. What would an enabling and inclusive healthcare system look like?\*

In order to address these questions, a series of four semi-structured qualitative workshops were organised with groups of marginalised women. As discussed above, we were keen not to silo women or suggest that women's lives and identities can be categorised neatly, however, to create a safe and enabling space which participants would feel comfortably sharing within, we had broad unifying themes for each workshop. Taking this approach meant that we were able to recruit participants via organisations they were already connected with and trusted. Based on the evidence review, we held four workshops with:

- Disabled Women
- Women of Minority Ethnicity
- Women Living in Socially and Economically Disadvantaged Communities
- Women Survivors of Violence and Abuse

Participation in the workshops was self-selective and open to anyone who identified as a woman over the age of 18 with direct experience of the workshop themes. There was a narrow eight-week timeline between initiation of recruitment to final report write-up which meant a maximum of four thematic workshops could take place.

<sup>8</sup> Although not a primary question, we were also interested in the social determinants of health inequalities and to hear directly from participants on what factors help or hinder good health and wellbeing. However, due to timing constraints this latter question was not fully explored.

CWI led the recruitment of participants by contacting organisations in the NWC membership network and using its connections to national and local organisations. Four different recruitment posters were developed highlighting the purpose of the project and what participants could expect in the session. A nominal contribution was provided in recognition of the time and commitments of the participants. Following indication of interest, prospective participants were advised that the session would be recorded to ensure accuracy in the analysis stage and provided with an agenda to ensure they were fully comfortable with participation.

Each of the four workshops had 9-19 women participants and lasted two hours with three facilitators supporting each session – two from CWI and one from the NWC, with the exception of the workshop with women of minority ethnicity which Dr. Marianne O'Shea from Maynooth University co-facilitated alongside CWI and NWC due to only one CWI facilitator being available on the date. The workshops took place over Zoom and were recorded with participant consent.

The workshops began with a presentation on the findings of the Women's Health Taskforce representative research which was undertaken by MCCP. This served as a springboard for discussion and this led to a free-flowing conversation on experiences of the health system and participants' recommendations for improvements, in line with the research question on what an enabling and inclusive system would look like. A topic guide was developed but as the conversation flowed there was very little need to prompt.

Thematic analysis was conducted on workshop notes to enable identification of recurring motifs and common concerns. The recommendations were developed through the solutions suggested by the participants and those identified by the researchers based on analysis of the problems highlighted in the workshop. The combined notes from the workshops were shared with participants after the session to allow opportunity for participants to highlight any inadvertent mistakes or misrepresentations



and where participants responded with clarifications or additional points, these were taken on board. A final version of the report complete with recommendations was also sent to participants and no participants sought any changes to the document or recommendation list.

For a full overview of groups contacted, workshop format, topic guide and recruitment posters, see Appendix A.

Finally, it is important to note that these workshops do not represent the totality of marginalised groups and we are conscious that there are many other groups of women who are at risk of poorer health experiences and outcomes, including trans women, homeless women and women who have grown up in state care. While efforts have been made to ensure the experiences of all marginalised women has been considered in the development of the Action Plan, further qualitative research with women not represented in this research would be helpful to ensure their experiences are fully reflected in future work on women's health.

## Ethics

In recognition of the challenging and sensitive nature of the subject matter, each workshop allocated time at the beginning to establish collective ground rules and expectations for how the session should be run to ensure everyone felt comfortable and able to share on their own terms. The contact details of the facilitator who had been the initial liaison and support were provided again at the end of the session in case any participant wanted to discuss anything further or needed to access follow-up support. For the survivors of violence and abuse workshop, an experienced domestic violence support worker joined the workshop, and she was available in a separate confidential break out room if participants needed in-session support. As outlined in the Methodology, participants were involved and updated at all stages of the research process to mitigate the risk that the final report would inadvertently misrepresent or misconstrue their views.

## Participant Demographics

In total, 50 women joined the workshops – two women joined two workshops meaning the total numbers in the workshops exceeds the total participants. 51 women filled out the online demographics form – this is due to the link being circulated in advance and one woman intending to come but who could not attend on the day.

The response rate for the demographics form was very good with all participants filling out the vast majority of questions. In general, the sample was quite different to the MCCP research sample, for example, it was much more ethnically diverse with just 65 per cent of women participants identifying as White Irish. The majority (almost 40 per cent) were aged between 35 and 44. There was roughly an even divide between rural and urban locations. A third of respondents lived in households where gross income was less than €40,000 in 2020 and a third were unemployed. Three-quarters of the sample had an undergraduate degree, with one quarter of these having a post-graduate as well. Approximately half were providing care to children and very few were providing care to other adults either at home or in the community.

#### **Findings:**

# Common Themes and NWC's Primary Recommendations

Detailed findings on each of the workshops are presented below, however, what emerged very clearly was that many of the barriers women face are not unique to specific groups of women. This underlines that work to improve access to and inclusion in healthcare would have far reaching benefits for multiple cohorts and generations of women who have historically been marginalised.

From analysing the discussion and integrating the concerns and solutions identified, NWC grouped issues into four core overarching recommendations:

- View women as equal partners
- Champion community-based care and community development support
- Promote accessibility and inclusion
- Collaborate across Government

#### View women as equal partners

While some of the women who participated did have positive experiences of care, for the vast majority, much of their engagement with the health service, and the system of support more broadly, was unsatisfactory. Participants' experiences resonated with the MCCP research finding that women's needs are being underserved through dismissive or belittling healthcare interactions and rushed consultations, coupled with insufficient information to progress the care pathway. Across all four workshops, women voiced frustration at the lack of being listened to and taken seriously and the examples they proffered suggest that women's right to health is being tempered by multiple and overlapping forms of bias around the intersection of gender with age, disability, class, race or ethnicity.

Across all workshops there was a strong view expressed that more needs to be done to ensure professionals are equipped with the knowledge and skills to work with diverse communities of women, whether this is disabled women, or women of colour or of minority ethnicity, or women who are experiencing trauma. To help ensure that women receive consistent care and are uniformly recognised as equal partners in all settings, grassroots groups of women and women who are experts by experience on different health conditions should be engaged to help improve training and support for professionals on a range of topics. Training should emphasise the importance of shared decision-making through marrying clinical best-practice with patient preference, and be mandatory, beginning in undergraduate curriculums and continuing across professional development.

Aligned to provision of enhanced training, focused measures to improve diversity and representation across all tiers of the health and social care workforce is necessary. For many women, the sense of an equal partnership was most present when they were supported by someone from a similar background. Here, good healthcare was characterised by being able to relate to the person and feeling you had a shared understanding. As such, much work needs to be done to improve access routes into healthcare professions and representation of diverse groups of women, particularly across senior positions. Not only would this help to redress employment inequalities and potentially increase service-user satisfaction, it would also likely deepen understandings of diversity and inclusion among the broader professional workforce.

## Champion community-based care and community development support

A second key recommendation to emerge was the need for greater consideration of the role community-based care can play in the care pathway. Across the workshops, women spoke enthusiastically about the accessibility of community support delivered by local organisations and this was often presented as an antidote to the complex network of services that women must navigate. Community support included but was not limited to specific health supports and encompassed informal classes through community resource centres, local support services for domestic abuse survivors, local mental health services, as well as more formalised peer-led primary health care projects. These findings suggest that there would be much value in greater investment in local projects, alongside greater awareness of local services by GPs so they could signpost to these. The findings also point to the potential role of social prescribing for health concerns such as loneliness or social isolation. Resources for community development work with women which prioritises empowerment, participation, inclusion and diversity should be central to the development of health policy and practice.

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Investment in community care, and improving regional coverage of this, is likely to be a valuable health prevention and promotion tool, however, it is critical that clear pathways between community care and support for more acute needs are in place. Systemic barriers such as prolonged wait-times and slow or fragmented referral pathways were endemic, and stories shared suggest the health system was working in siloes in some areas. In other cases, community help was unable to provide the level of specialist support needed to enable recovery, and participants were left to navigate the public or indeed private system alone. It is therefore vital that any additional investment in expanding local care and community support is accompanied with a clear understanding of how this fits within the broader system to ensure timely and smooth referral pathways.

#### Promote accessibility and inclusion

As in the MCCP research, this research confirmed that the burden of navigating a complex system was immense, and women expressed clearly that more needs to be done to ensure care pathways and consultations are more accessible and inclusive. While participants considered accessibility and inclusion through many lenses, the underlying point was that the current configuration of care does not enable marginalised women to engage as equal partners. Accessibility relates not only to the built environment and universal design, but also to the supports available to the service user to enable them to be listened to and taken seriously in shared decision-making, for example, interpretation and translations services for foreign languages and Irish sign-language, as well as simple information on diagnosis and the next steps for recovery that were accessible to everyone and took account of different levels of education and literacy. The absence of accessible, practical information - particularly for children's health conditions and their treatment plan – left women in limbo and was clearly taking a significant toll on women's health and exacerbating health needs. This suggests that focused work to improve experience of care through mainstreaming inclusive and empathetic provider-user interactions, alongside clear and simple supplementary resources, could have a significant protective impact and may mitigate the risk that women's health does not deteriorate further.



#### **Collaborate across Government**

It is clear to NWC from the insights gathered in the workshops that work to improve the health outcomes of marginalised women will require crossgovernment collaboration. Many of the health needs which participants spoke to, as well as the barriers in access to care, were rooted in common universal drivers of marginalisation, including poverty, deprivation, racism, gender-based violence, social exclusion, ableism, family hardships, and trauma. The stories that women shared reinforced the overwhelming evidence that these significant social problems have a significant detrimental impact on health outcomes and access to care and can occur in intergenerational cycles if timely support is not provided. The issues ranged from the absence of comprehensive health and sexuality education in schools, to childcare challenges, barriers and challenges in family courts system and child protection services, impact of Direct Provision system and legal aid and medical card thresholds. The participants clearly articulated the many factors which impact and undermine women's health, underlining the need for a coordinated, whole of Government approach to improve outcomes. This is even more pressing in the context of Covid-19 which has widened health inequalities, with the most disadvantaged disproportionately impacted.9

<sup>9</sup> Patel, J. A., Nielsen, F., Badiani, A. A., Assi, S., Unadkat, V. A., Patel, B., Ravindrane, R., & Wardle, H. (2020). Poverty, inequality and COVID-19: the forgotten vulnerable. *Public health*, 183, 110–111.

#### **Findings:**

### Disabled Women



Seventeen women joined the disabled women's radical listening workshop and they identified as having diverse genetic, neurological, physical and neurodevelopmental health conditions, with some women having multiple diagnoses.

The discussion which ensued touched on several major themes: overarching systemic barriers to care, including public-private inequalities, fragmented care pathways, and lack of specialist knowledge amongst health professionals; barriers specific to the intersection of gender and disability; and accessibility and inclusion.

Reproductive and sexual health was an area of particular interest for the group and their concerns and recommendations around this are also detailed below.

'The entire system is set up for coping, not thriving... to access supports you have to be barely coping'.

#### **Systemic Barriers to Care**

Participants identified a series of systemic factors which disproportionately impact the disabled community given their greater health needs.

The public-private divide was recognised as one of the single biggest barriers to accessing care in line with needs and rights, with participants highlighting that certain medicine is not covered by long-term illness payments even when a person's condition will not change, and they will require this medication continuously. Medical items such as drops and ointments are frequently not covered either.

Experiences of the public system were poor and there was significant concern amongst the group that disabled women often need to reach crisis point before they are taken seriously. Women spoke of facing significant waiting lists for a range of health issues which act as a barrier to timely care: 'the entire system is set up for coping, not thriving... to access supports you have to be barely coping'. Questions were raised around trauma-informed care and what it means and some participants spoke of how their personal experiences led to re-traumatisation. Some women had experienced fragmented care pathways and described how the burden of navigation was often placed on the disabled woman as service user and that accessible and accurate information was often not being readily available. The hospital care model was discussed and there was a feeling that women should be able to access care in the community with appropriate supports in place for staff and service users.

Participants also raised concerns related to workforce and specialist knowledge and expertise. They highlighted that there are added challenges for disabled women in accessing evidence-based care, particularly when professionals with appropriate qualifications are unavailable in an geographical area or in the country. There was agreement that greater attention needed to be paid in medical training to understanding the intersection of some physical and mental health conditions with disability, as the complexity of certain presentations can mean standard treatment will not be suitable.

It was highlighted by the participants that for disabled women in direct provision there are significant challenges especially for those who do not have a medical card or who are moved from city to city and centre to centre. These women need support and coordination of health services when they are being moved from place to place. Frequently those on medical cards are requested to update their personal details even when their card is not up for renewal. This has proven stressful for some people.

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## NWC recommendations to address systemic barriers to care:

Tackle public-private inequalities by ensuring that work to improve women's health experiences and outcomes is aligned with Sláintecare.

Develop a UNCRPD
Fidelity Framework for
the health system to
ensure disabled people are
guaranteed their right to
health when interacting
with the service.

Broaden access to medical cards to include disabled people with long-term conditions which will not change.

Make disability
awareness training - grounded
in the rights-based approach
and social model of disability
- a mandatory component
of core medical training,
including for doctors, nurses,
midwives and dentists.

Expand medical training to ensure that professionals understand how conditions interact and exacerbate each other and encourage the development of sub-specialities.

Improve coverage for services particularly in rural Ireland and consider the development of Centres for Excellence to combat fragmented referral pathways and geographical barriers to accessing high-quality care.

Ensure that women in direct provision have expedited access to medical cards and that there is a care plan in place to ensure that a change in location does not lead to break in healthcare access.

'Going in in my early 20s and saying to a doctor sex is painful and them saying it's just the way you are built, nothing we can do for you.'

## Disability and gender bias in delivery of care

A recurring theme which emerged was that disabled women as experts by experience felt they were not listened to or taken seriously. Participants raised numerous diverse examples of how their experiences had been dismissed, highlighting how some professionals showed a lack of interest or empathy when responding to issues raised.

'Going in in my early 20s and saying to a doctor sex is painful and them saying it's just the way you are built, nothing we can do for you.'

Feelings of being dismissed or not seen as an equal partner appear to have been compounded by the willingness of some professionals to speak to male stakeholders: 'They spoke a lot to my husband when he was with me instead of me. There was very little bedside manner to inform me I was losing my baby at the time a couple of years ago.... I was in limbo for a time ... (it was) very stressful eventually I had procedure in National Maternity hospital, but it was a hard time in my life and very little information given for support for this bereavement.'

One woman observed that sometimes it felt like the only diagnosis available to disabled women was depression or anxiety due to the lack of awareness of how certain conditions manifest in women, including but not limited to neurodivergent conditions such as ADHD or autism. Prolonged delays in identification and access to support impacted on quality of life, with women feeling they had to take on the role of advocate in order to receive support in line with their rights.

While some women underlined that there should be a right to a second opinion, it was evident that for others, initial poor experiences had a clear detrimental effect on confidence and willingness to engage further. One woman spoke about how a series of poor experiences related to her genetic condition which she identified as 'gaslighting' meant she was reluctant to attend. 'Going to so many different doctors, I was told it was all in my head, it was depression, it was anxiety'. These experiences took a significant toll on her: 'I get so anxious and so nervous anytime I go and see any form of medical professional now'.



Similarly, another woman spoke about how a negative experience of cervical screening means she has not had another test in over eleven years. 'When I went for my smear test in 2011 there was a big production of why do you need it if you're not sexually active...it was only my PA was with me to bring in the hoist. We had to basically make everything accessible for me and it put me off so much that I haven't had a smear test since'.

Recounting poor interpersonal exchanges between some professionals and women led participants to discuss training and provision of support for staff. . . One woman spoke about how, having viewed the existing HSE training for health professionals on disability, she found it very concerning, particularly in relation to neurodivergent conditions: 'at best it was ableist and at worst it was downright damaging'. There was a strong feeling within the group that as experts by experience, the disabled community should be at the forefront of health system reform and training material development: 'we need to be pushing our voices, our solutions and our conversations onto those kinds of platforms'. The emerging role of Patient and Public Involvement (PPI) in research was pointed to as a potential model to explore. Similarly, concerns were expressed around the National Consent Policy and legislative frameworks and the need for review and revision. Aligned to this, another woman spoke



about noticing a shift in the messaging and official supports available to her as she entered older age: 'It's like I have been put in another category without my permission... I now feel like I am being prepared for dying as opposed to living.' Another participant raised that for some young disabled women, their youth can be something which health or social care practitioners are taken aback by and do not know how to interact or support appropriately.

The experiences of disabled women raise important questions regarding bias and discrimination, both on a system level and in individual service user-provider relationships. Participants highlighted that the system could be significantly improved through reframing the relationship to one which recognised and valued disabled women.

## NWC recommendations to ensure rights-based, person-centred care:

Ensure disabled
women are at the centre
of all decisions
surrounding their supports
and are seen as an
equal partner.

Reframe the narrative – 'ask what matters to you? rather than what is the matter with you?' Ensure the codes of practice already designed in the Assisted Decision-Making Act are applied across the health sector and put service user will and preference at the core of all engagement with the HSE.

Develop a new
approach to training for health
and social care professionals by
working in partnership with those
with lived experience; the HSE
should work with Disabled Person
Organisations as equal partners
following the model of the LGBT
Ireland equality training which
is on the HSE training
portal.

Consider the model
of Patient and Public
Involvement (PPI) in
research projects to see if
lessons can be drawn for user
involvement in health service
design and delivery.

Support Public
Health Nurses to
specialise and develop
their communication skills,
receiving the appropriate
training to work with all-age
cohorts with multiple and
diverse needs.

Develop gendersensitive training for
medical professionals to
highlight how conditions
can differ in presentation in
men and women to support
earlier identification and
support.

Analyse
disaggregated data
to better understand
disabled people's use of
the health system and
develop policy in line
with needs.

Review the
National Consent
Policy to ensure it
supports shared decision
making and service
user engagement
for all.

Amend 'Your Service Your Say' to give specific recognition of the unique experiences of people with disabilities and treat their complaints accordingly.

#### **Accessibility and Inclusion**

Accessibility was expressed as a key issue for all the participants, both in terms of redressing bias in the built environment and enabling service-user involvement in care pathway decision-making. Universal design planning for new hospital health facilities was raised as an important area to develop. One woman said in the summary of the discussion, 'we kept coming back to challenging systemic ableism'. Examples were given around inabilities to access mammograms and cervical smear tests, with the underlying sense that that the service user was made to feel like a nuisance rather than a holder of rights.

'I was supposed to have a mammogram but I'm a wheelchair user and I couldn't have the mammogram because it wasn't accessible. My passion is that if things are made accessible for people with disability ....it makes things available for the whole population'.

Another participant flagged the lack of appropriate supports for deaf women in terms of sign interpreting and the challenges in ensuring that medical professionals are there at the same time as sign interpreters. Poor accessibility can also be seen in terms of the lack of appropriate information provided to women and the barriers that this presented for understanding what a diagnosis may mean and what supports are available: [The system] is 'constantly placing the administrative and informational load on the individual person'.

The impact on wider family was also highlighted. For example, when trying to support her mother in a state of acute need, one participant was told she would have to move out of the Accident and Emergency Department as her chair was taking up space. 'Not only was I being discriminated against, but more importantly my mum was being discriminated because her daughter was disabled.'

'I was supposed to have a mammogram but I'm a wheelchair user and I couldn't have the mammogram because it wasn't accessible. My passion is that if things are made accessible for people with disability ...it makes things available for the whole population'.

There was also recognition that more needs to be done to represent a diverse range of disabled women in health campaigns, not just a wheelchair user. In these campaigns, disabled women should be seen in a variety of roles: as service-users, as carers, as mothers and daughters to ensure visibility.

One positive which has come out of the experience of the pandemic has been reform of the health system to allow remote access consultation. Participants spoke about how this has really enabled access and innovations such as this should be built on and sustained. For example, development of an accessible online booking system for appointments was seen as likely to be particularly advantageous.

The role of Personal Assistants (PA) was also raised as particularly important for supporting access and inclusion and that the state must recognise the key role PAs play in independent living. Disabled people should be directly involved in the training of PAs to ensure this training is robust and service-user oriented.



## NWC recommendations to improve accessibility and inclusion:

Give more
recognition to innovative
solutions and, where they
work, mainstream them.
For example, maintain
telemedicine and develop
a user-friendly online
booking system.

Recognise that
disabled women can
have additional difficulties
accessing information and
therefore information
must be simplified and
made accessible in various
formats.

When developing health campaigns ensure disabled women in all their diversity are represented to signal that our health service is there for everyone.

Champion universal
design planning and ensure
that all services are provided to
disabled women as they would
their able-bodied peers - make
the necessary accommodations
to settings to ensure that all
women can receive care in line
with their rights.

Develop a train
the trainers programme for
disabled people and ensure
that all PA training is of
the highest international
professional standards and
is delivered in whole or in
part by disabled people.

Ensure that all
disabled women who need a
Personal Assistant have access to
this support, empowering them to
manage their own career needs,
considering in particular the case
of visually impaired women
and those with intellectual
disabilities.

#### **Sexual and Reproductive Health**

A major focus of the discussion was on disabled women's sexuality. There was a concern raised by the women that disabled women are seen as disabled above and beyond everything else.

Participants noted that negative assumptions about disabled women and sexuality are widespread including that disabled women cannot have children and the difficulties associated with assisted fertility, and this can contribute to the discrimination experienced by disabled women who want to be or are mothers. "[there is an] assumption not to ask a woman with disability if they are pregnant or if they know their rights in relation to that"

One participant raised a concern regarding the restrictions in maternity services and how they were having a significant adverse impact on disabled women, especially those who need a Personal Assistant. The importance of supporting informed decision around reproductive health was underlined by some participants and they also raised that genetic testing should be made available to facilitate this.

Participants spoke about societal judgement and ignorance surrounding disability, sexuality and sexual health. One woman described being challenged around why she needed to access a cervical smear test if she was not sexually active.

There was consensus that more sex education is needed in schools and this should be inclusive of both disability and LGBTQ identities. One woman also raised the importance of representation and seeing disabled women in the media and online discussing issues of sexual health and abuse. It was highlighted that there must be more supports for victims and survivors of sexual abuse and that these must be accessible to disabled women.

## NWC recommendations on improving sexual and reproductive health:

Develop inclusive and rights-based sexuality education that supports all girls, including disabled girls, to understand sexuality and sexual development and to help shift societal narratives on this.

Ensure that all professionals working in the health and social care space are alert to their own unconscious biases, particularly around disability and sexuality.

Provide genetic testing to ensure women who may have genetically inherited conditions can make informed decisions about fertility.

Consider the disproportionate impact that universal policies such as restrictions in maternity hospitals may have on marginalised groups, for example disabled women.

Invest in and expand inclusive support services for victims and survivors of sexual abuse to ensure all disabled women who have experienced trauma can access evidence-based and appropriate healthcare.

#### **Findings:**

# Women in disadvantaged communities

Nine women from diverse socio-economically disadvantaged communities joined this workshop. Some identified as single parents or teenage parents and others as part of or representing the Traveller community or those of migrant background and in Direct Provision.

The discussion highlighted the burden of care which women as mothers experience and the role they have to play as advocates, fighting and navigating the system for their families and particularly their children. Here, like in other workshops, women spoke about informational barriers and the absence of accurate and accessible material. Two other key aspects of the discussion were sexual and reproductive health, and the role community care plays in building solidarity and supporting positive health and wellbeing. These themes are explored in greater detail below.

#### Navigating a Challenging System

A very strong theme which emerged was the frustration at navigating the health system for children, particularly those with additional needs. The women highlighted the gaps and barriers in care through reference to their children's needs. Multiple women shared stories about prolonged delays in accessing support, highlighting a lack of structure and join-up even where initial assessments have taken place.

'You are literally just told something is wrong with your child, go figure it out yourself ... you are thrown in a dark alley, and you have to fight your way out, if you find a torch fair play to you but if you don't you are going in blind.'

The women strongly expressed the view that the burden of navigation and accessing care for children was their responsibility and it was the mothers who carry the weight of this responsibility. As another woman said:

'And as the mother, and as the woman, you are expected to advocate and push and put yourself under unbearable amounts of stress and pressure the whole time trying to advocate for what you know your child needs.'

'You are literally just told something is wrong with your child, go figure it out yourself ... you are thrown in a dark alley, and you have to fight your way out, if you find a torch fair play to you but if you don't you are going in blind.'

A key issue expressed by the women was the lack of accessible information on the care pathway, with the participants highlighting the negative consequences for those who haven't had advanced education or knowledge of local services, or who have English as an additional language. As one woman said:

T've got a college education ... and I'd be quite booksmart but I'd often say to my mam 'how are people navigating through this whole thing who don't have this same booksmart.'

Another woman reflected on her sister's experience, highlighting how challenges in understanding the information are compounded by the stress and anxiety that the situation induces:

'There's a language barrier there, like you have to come down to the level here where you have to explain it, and the person may be a bit upset and then you have to re-explain it again.'

Women also expressed the view that in many of their cases the burden of navigating the HSE was compounded by simultaneously grappling with family courts, abusive ex-partners and trying to arrange childcare to be able to attend appointments. One woman highlighted that for many in the group they were navigating both health and other systems such as family courts simultaneously and the negative impact that had on their health and wellbeing:

'There's no help there for the mammies to deal with all of this.'

As another woman said, all of this is leading to

'constant stress that we as the mothers are under ... you literally find it hard to take a breath yourself.'

## NWC Recommendations to address systemic barriers to accessing care:

Accessible step-by-step guides should be produced which outline the different stages of the care pathway, what can be expected at each point and what the statutory timeframes are, for example for children with additional needs, the guide should cover the steps which follow the Assessment of Need.

A case management system should be developed for children with additional needs, i.e. there should be one person who is responsible for ensuring care needs are being met by the various parts of the system to help shift the burden of responsibility from the mother.

Information on care pathways and treatment supports should be available in multiple languages.

Cross-governmental work
is required to address barriers in
women's access to healthcare and
mitigate risk of poor mental health
and wellbeing from cumulative effects
of navigating an adversarial system.
The Department of Health must make
the case for a 'health in all policies'
approach, especially when considering
reforms of the family court system
and development of the public
childcare model.



## Care Pathways and Service Provider-User Relationships

Women shared experiences of feeling belittled and of rushed interactions with doctors e.g being 'talked over', 'feeling concerns were ignored'. Women spoke of not being informed of follow-up supports or having clarity on what service is responsible for the next stage in the care plan or what support could be provided for recovery. As one woman said: 'I was left with the news and the two doctors were speaking to each other about it [my injuries] and they only stopped because they noticed I was crying. I was shocked and I'm a very assertive person, but I just felt I was stranded'.

In relation to mental health, the participants expressed views that the quality of the services need to improve. Again, the importance of connection was a key theme that emerged, with one woman highlighting that delays in access to medical cards meant having to access support through telephone lines. Not being able to see a person face-to-face made it much harder for her to experience a sense of empathy and have the comfort of being listened to.

## NWC recommendations to support rights-based and person-centred care

Unconscious bias
training for health and social
care professionals should address
latent gender bias and dismissal
of women's experiences or voices.
Greater focus should be placed on
interpersonal skills to ensure all
service user-provider interactions are
characterised by respect, dignity
and empathy.

Invest in and champion
mental health support so that it
is more readily available, with a
particular focus on therapeutic faceto-face support. Specific supports
are required for women in direct
provision, particularly when there
are delays in accessing a
medical card.



### 'Women feel totally not heard when it comes to that stage [menopause] in their life, they don't know what to expect'.

#### **Reproductive and Sexual Health**

As in other workshops, participants naturally landed on issues around reproductive and sexual health given the salience of this to women.

There were particularly serious issues raised relating to maternity care. One woman spoke about how a friend in Direct Provision asked for help when her waters broke but did not receive it and she ended up giving birth in her room with only her husband and no medical support:

'I feel if the mother is already feeling like she's contracting, she wants to give birth, I think the most important thing is to have her go into the hospital, just for her to even feel relaxed and okay she's going to give birth and she's in a safe place. She says she called around 8, 11, 1 and then the baby later came about 3 and the ambulance didn't come until like two hours after she gave birth in the room.'

She also highlighted how another woman in labour was sent back to Direct Provision as her GP said her labour was not sufficiently progressed to admit her and she was only able to enter hospital at the eleventh hour.

Additional areas highlighted as requiring further attention and support were miscarriage and the menopause. One woman described a lack of support for miscarriage, there is 'totally no support, no follow up support, nothing that anyone can tap back into'.

Menopause also prominently featured in the issues raised by participants, and a lack of awareness and information on how to navigate the menopause was raised: 'women feel totally not heard when it comes to that stage in their life, they don't know what to expect'. The cost of menopausal medication was identified as a real issue, particularly for the group of women who neither qualify for a medical card nor are on high incomes. The fear of taking Hormonal Replacement Therapy (HRT) was also identified, and though the research underpinning this fear has been disproven, it was clear from the participants that it continues to persist. Participants also highlighted that there is no education in schools on the menopause and it is still surrounded by stigma and can be an issue of ridicule – 'most men find it a laughing matter'.

Women tied the need for greater education on menopause to the need for better and more comprehensive education on relationships, sexuality and health in school. Age-appropriate education from a young age was seen as vital for challenging assumptions and stereotyping of women and girls. As one participant said this education should ensure girls know 'you do have a right to speak up'.

## NWC Recommendations to improve reproductive and sexual health:

Review pregnancy care pathway and identify circumstances where the mother may be eligible to enter hospital early to mitigate adverse impact on mother or infant health, for example, being in higher risk environments including but not limited to Direct Provision.

Provide greater training and support for staff on responding to miscarriage or still birth and ensure that there is an aftercare plan in place for all women.

Ensure that the forthcoming RSE curriculum is comprehensive and rights-based, covering all relevant topics in an age-appropriate way, including the menopause. Schools should be required to signpost to supports available in local community and ensure all children know where they can access help for a range of issues.

#### **Community Care and Early Help**

A very strong theme which emerged from this group was the importance of their community in health promotion and prevention, particularly in the context of Covid-19 when women may be experiencing additional loneliness or isolation. Multiple women spoke about the importance of community-based supports and the trust and solidarity they can engender. Some discussion was given to the role of supports like exercise groups, gardening, education, and cookery courses for generating a sense of connection and supporting collective resilience. As one woman said: 'it kept us all going... it wasn't even in the cooking it was the talking to people ... you had a friend and it was on zoom but they were still there.'

The merits of community-led peer interventions were also discussed and one woman expressed the view that the model of peer led primary healthcare that exists within the Traveller community may be helpful for other communities as well, such as migrant or disadvantaged communities.

'People and families work with those that they trust, do you know what I mean? And that's where you see better engagement because you're comfortable, at you know, at a normal level, a level playing field, we're equal.'

Wider access to peer led support was seen as a way to address language barriers in access to healthcare.

'It kept us all going... it wasn't even in the cooking it was the talking to people ... you had a friend and it was on zoom but they were still there.'

# NWC Recommendations to support care in the community:

Prioritise and invest in community supports in recognition of the valuable role community groups play in generating solidary and health promotion and prevention.

Encourage the mainstreaming of social prescribing in primary care to ensure that more people are made aware of and connected with local community groups as a prevention and health promotion tool.

Examine the viability
of introducing peer-led primary
health care, such as exists for
the Traveller community, for
other communities, particularly
migrant communities, and those
living in socio-economically
disadvantaged areas.

#### Findings:

### Survivors of the Violence of Domestic Abuse

Nine women participated in this workshop having experienced domestic abuse. The primary motivation for participation was a desire to try and change the system response to ensure that other women and children can access vital support. For several women this was their first time joining a consultation such as this and they were keen to offer ideas as to how the health and justice systems could be improved to better support other women and children who have experience of domestic abuse.

Many overlapping themes arose from a far-ranging discussion, these were: the barriers to accessing good health care; the adverse impacts of the justice process on women's health; concerns surrounding child safeguarding procedure; the financial barriers to recovery; and secondary victimisation from a fragmented system response. Each is discussed in further detail below.

#### **Barriers to Accessing Good Health Care.**

Women expressed views regarding a lack of professional understanding of domestic abuse in relation to healthcare interactions. One woman described when she presented with injuries in hospital no questions were asked around domestic abuse. Similarly, another woman had to argue with her obstetrician to ensure they provided a letter to allow her not to stand during court proceedings given the strain that successive days of standing would place on her. She highlighted how it was viewed as though: 'it was a shameful thing to be asking, it was like I was a criminal just trying to get a get out of jail free card to not stand in court.'

Experiences with GPs were mixed with positive and negative experiences reported. Several in the group spoke of how GPs failed to recognise signs of coercive or abusive behaviour and women shared stories of how abusive partners successfully manipulated their local GPs into questioning their sanity or ability to cope – one woman described her experience:

'forced to have a mental health check because I was seen as this absolutely crazy mother... they [abusive partners] are very good liars, and they turn the whole system against you'.





Other participants described similar experiences:

'you feel very isolated because they (abusive partner) make out that you are the crazy one and that you are the one who needs help, but actually you are just trying to find a voice and say this isn't right, so it is a very lonely time.'

Another participant highlighted how her abusive partner received the attention from social work and health professionals at the expense of herself and her children,

'No one ever took the time to think how I was affected, how my three kids were affected, I had an autistic child, I had just got the diagnosis, I just got a demand letter from the banks coming to take the house, no one came and asked if we were okay.'

She highlighted how her GP was preoccupied with her partner's health and wellbeing and didn't support her own:

'all the focus went onto him, they didn't seem concerned about the substance abuse, they were concerned about his mental health, eventually at the end of it, they turned around and said we hope you don't have burn out because I was the only one looking after the three kids and then in the end I changed GPs.'

'you feel very isolated because they [abusive partner] make out that you are the crazy one and that you are the one who needs help, but actually you are just trying to find a voice and say this isn't right, so it is a very lonely time.'

In some examples where women received support from GP's, the experiences also point to the need for a greater trauma informed approach. For example, one woman spoke about how her GP asked what she felt were overly intrusive questions about specifics of an assault on her and this contributed to her experience of secondary trauma. Another woman described how the act of speaking about the abuse was very upsetting and this was compounded by having to walk back through the main surgery with other members of the small community witnessing her distress.

Women described how the process of trying to get help is very challenging and takes a toll:

'I would say there is actually no supports and you have to fight constantly to be seen, to be heard with your GP, with psychologists, with psychiatrists.'

Women also expressed views in relation to how successive poor experiences of healthcare eroded their trust in the system and led to some women withdrawing from visiting GPs or core services, with significant impacts on their own and their children's health. As one woman said,

'There's a lasting effect, my son didn't get the help that he needed when he was little [and experiencing domestic abuse] and he's now a teenager and I didn't get the support that I needed either.'

Finally, one woman made the point that coercive control makes you blame yourself and protect the abuser and that even being able to see a GP can be challenging if you are not at a stage where you recognise what is happening as abuse. This was also echoed by another participant:

'For me, I didn't understand that domestic violence was more than physical, the mental, the emotional, the financial abuse as well so I think there should be more explanation for that.'

Twould say there is actually no supports and you have to fight constantly to be seen, to be heard with your GP, with psychologists, with psychiatrist.'

### NWC Recommendations to challenge patriarchal bias and lack of victim-focus:

Explore feasibility of international models of good practice in primary care such as the UK's Identification and Referral to Improve Safety intervention to improve support for women subjected to domestic abuse and ensure access to timely and appropriate healthcare.

Develop the health system's own capacity, skills, knowledge and understanding of domestic abuse, including coercive control, through intensive and mandatory training for all health service providers across primary and hospital care. Ensure that comprehensive training and education on domestic abuse equips professionals to identify victim-survivors of domestic abuse in a sensitive and service-user oriented way. Ensure support pathways are well established and embedded within all primary care and hospital care.

Ensure that all responses
to domestic abuse are victim-focussed
and developed through shared
decision-making which respects the
views and experiences of the woman
impacted. The primary objective
must be to safeguard and promote the
rights of women and children first and
provide support in line with
their needs.

Develop public awareness campaigns on all forms of domestic abuse, including coercive control and financial abuse, so that there is greater knowledge and understanding of how abuse can manifest and what to do if you are affected by it or believe someone you know is.

Develop and resource victim centred, pragmatic guidance to medical centres to highlight how in cases of women and children experiencing domestic abuse additional supports should be considered to enable them to access healthcare on their own terms, for example, flexibility in opening hours of the surgery or allowing survivors to use back doors if this is what they wish.

### The adverse impacts of the justice process on women's health

The women in the group spoke about how their mental and physical health and safety are intrinsically linked to the justice system. The stress and demands of engaging with the criminal justice system were identified as undermining women's health particularly their mental health. The discussions led to women highlighting the changes they would like to see in the justice process and raise important questions regarding the need for a holistic and intersectional approach between health and justice to improve women's health.

Examples shared within the group suggest that in several cases women struggled to be heard and taken seriously, and the system response frequently failed to give weight to their voices or allow them any agency in decision-making. For example, one participant pointed out that she and her children were moved, against her will, from her own geographical away from her family, friends and support network in order to escape her partner.

Experiences of the guards, like that of GPs, was mixed with some reporting positive and supportive experiences, while others raised significant concerns. One participant noted that she felt scared of the guards after having challenging experiences when reporting a breach of the safety order

"... they had no interest in my safety, it was like I was bothering them."

In another case a woman described how she was given incorrect information by local guards with regard to enforcement of a safety order leading to her feeling very confused and uncertain.

One woman of migrant background spoke of what she felt was a power imbalance between her and the local guards, which in her view, was due to the tight-knit nature of the rural community which her abusive partner was from. She described that every time she tried to report issues to do with a safety order breech she was told

'oh but did he really do something to you, that kind of thing and thousands of questions like why, are you sure? In this town [small rural town] everyone knows everyone, and I know Guards know his parents, he knows Guards, everyone knows each other so I felt like it was kind of trying to avoid kind of making any problems.'

She felt her disclosures were dismissed and downplayed and she was made to feel she was 'exaggerating'. Only once was she told she could make an official report. She felt the particular treatment she received was shaped by her status as a woman of migrant background, based on the idea 'you're not from here, we're defending our people'. This links to other views expressed in the workshop by minority ethnic women that women of migrant background face dual discrimination in having their voices heard.

The views expressed by these women raise important questions regarding how women feel heard and believed and their view that the justice systems can be and is manipulated by abusive partners. This was clearly identified as having a very significant impact on women's mental and emotional well-being.

Some experiences with the guards were positive and this played a crucial role in supporting the safety and health and wellbeing of women. As one woman said the 'guards were amazing with me, they were the ones telling me to get protective order' and recounting how they continued to act swiftly for her safety.

Women spoke about the challenges of going through court proceedings and the difficult nature of the process. One woman highlighted how beta blockers are prescribed for PTSD and this can impact ability to engage. Several women shared stories that highlighted the toll that navigating such a process takes, as another woman said:

'I had to beg and I had to fight hard and I think the justice system is a disgrace when it comes to children ... the kids saw everything, they have everything locked into their little heads, whatever about me... they didn't get any care, no safety, protection... they never were considered.'

Several concerns were raised around the impact of the in-camera rule and how challenging this is for shedding light on the issue of domestic abuse and for women in advocating for their rights: 'someone is being dragged through a system by a perpetrator, and they are not allowed talk about it...it's a major human rights abuse ... individually none of us are allowed speak and we are not being listened to.'

She suggested that 'if the in camera rule could be lifted slightly so [the Department of] Health could see what was happening to people in the Justice system, in family courts ... we are destroying women's health by making them jump through these hoops when they are already victims,'

The views expressed by the women in the domestic abuse workshop showed the inter-relationship between their experience of the justice system and its impact on their health and well-being.

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### NWC Recommendations to support better integration of trauma informed health and justice policies:

The Department of Health to proactively engage with Department of Justice to reform the court system to integrate a trauma-informed approach. Reform must include specialist training for all court professionals, on abuse, including domestic abuse, the impacts this can have on survivors and the strategies perpetrators deploy to obscure blame. Consideration could be given to the Scottish reforms currently underway and the lessons that can be drawn from that (can we give a reference to this).

The Department of
Health should engage with the
Department of Justice to explore
the impact of the in-camera rule
on victims of domestic abuse and
the secrecy and fear it can
create for victims.

The Department of Health should emphasise the need for review and expansion of the training for guards on domestic abuse when working collaboratively with the Department of Justice. Training should be mandatory and comprehensive and should cover interpersonal skills as well as referral pathways and join-up with other relevant statutory and community services.

The Department of Health,
working with colleagues across
Government departments and
agencies, should develop additional
resources to enhance health
professionals' knowledge of the
overlap between the health and justice
system, underlining the need for
quick and timely sharing of records
to support court proceedings and how
medical evidence is used.

#### **Child safeguarding concerns**

Several women raised serious concerns with regard to their interaction with Tusla. One woman expressed the view -

'I find it really sad that Tusla are supposed to be there to support, but you rather find them threatening more, I found my fight with Tusla was as bad as my fight with my ex'.

In particular, the issue of enabling paternal contact with children in cases of domestic abuse was raised by all the women with children. They described how this caused them considerable distress and they didn't feel their concerns were being listened to or taken seriously. As another woman said:

'The system is seriously damaged, like my child was going through a terrible, terrible time and still the Tusla was pushing, 'it doesn't matter what he is, how he is, he's his father, that's the most important thing, no one was thinking about how this child is affected.'

She reported that this was despite her son saying in his interview with Tusla,

T'm scared of my dad, I don't want to see him, I don't want to see him at all. I'm afraid he is going to hurt my mom and hurt everyone around me.' Although these concerns were raised, contact was still enforced.

In a third example, a participant reported that although Tusla received multiple reports of possible child sexual abuse from professionals and family members, contact between the father and child was maintained following separation. This caused the woman considerable distress

'Tusla is my main issue, they did not protect my child ...they protected him [the abusive partner], they said if you don't stop arguing with this man, we are going to take your child off you'.

The participant shared that several years later, her son disclosed to her that his father had groomed him for sexual abuse at that time. On hearing this disclosure, the participant brought her son to the Guards to report it and so they could liaise with Tusla on this. Yet despite this formal report, she has had no subsequent contact from Tusla regarding the investigation or followon support for her family.<sup>10</sup>

In addition, several women spoke about the absence of therapeutic support for their children which was a cause of significant concern. One woman said she did eventually receive help from CAMHS for her younger child - although nothing for her older child – and that the help has been very good for him.

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<sup>10</sup> As part of the ground rules, we established that this workshop was a safe space and women could share as much or as little of their experiences as they felt comfortable with and could share on their own terms. In this instance, the participant shared additional details of her experience with NWC after the workshop for inclusion in this report. Children First guidance encourages public reporting of all child welfare and protection concerns to Tusla and legally obliges certain mandated persons to report. In this instance as the case was already known to both Tusla and the Guards, NWC determined that the case did not need to be reported. Following subsequent queries from the Department of Health, we clarified our responsibilities with the Tusla duty social work team who confirmed no report was required.

## NWC recommendations to support children as victims of domestic abuse:

Children need to be recognised as victims of domestic abuse in their own right within all government departments and agencies.

Review the model of working between Tusla and CAMHS to ensure that all children who have experienced domestic abuse can receive evidence-based and agappropriate therapeutic support if required. Maximum wait times between referral and assessment, and assessment and treatment should be introduced to ensure that care is provided swiftly and there is accountability within the system for supporting children's recovery.

Child protection services delivered by Tusla should be independently reviewed to investigate systemic bias towards maintaining contact with fathers in situations of coercive control and domestic abuse.

#### **Financial barriers to recovery**

Women highlighted the financial barriers that arose from the burden of medical evidence for the courts – for example, one woman described paying €350 for a doctor's report for the solicitor. Similarly, another woman described having to get an MRI scan which could not be offered on the public system and had to be obtained privately at a high cost.

Some women also spoke emphatically about the need for publicly funded therapeutic trauma services and counselling, highlighting the challenges with having to fund evidence-based treatments privately.

Financial barriers in the social welfare and taxation system were also raised by some women, they expressed concern that they could not access payments or be treated as individuals.

We're not seen as individuals; we're just seen as a marriage, so we are dependent on them [abusive partners] with revenue'.

Many of the women also raised that they were not receiving child support from their former partners and for those that had orders in place they described how there was no mechanism for enforcement. When sharing these stories, it was evident that the lack of financial support was taking a significant toll on the women's health. The issue of thresholds for legal aid and the complexity of calculating eligibility in cases of domestic abuse criminal cases were also raised.

'We're not seen as individuals; we're just seen as a marriage, so we are dependent on them [abusive partners] with revenue.'



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## NWC Recommendations to address financial barriers to recovery:

Increase funding for mental health services, with a particular focus on expanding public provision of gender-sensitive and evidence-based trauma services for survivors of domestic abuse.

The Department
of Health should engage in
cross-departmental work to
consider eligibility thresholds
for social protection and
legal aid in cases of
domestic abuse.

The Department of
Health and Department of Justice
to review the current policy
surrounding provision of medical
evidence for court proceedings in
cases of domestic abuse to ascertain
if this could be subsidised. This
would help mitigate the risk that
service-users who are already at risk
of experiencing financial abuse, do
not incur additional
personal costs.

Establish an
Independent Agency
to oversee Child
Maintenance.

### A fragmented system response compounding women's trauma

Perhaps the most dominant theme to emerge from the domestic abuse workshop was the lack of joined-up approach in core services and how this contributed to the trauma they and their children experienced and inhibited their recovery. As one woman said:

With the services at the moment you are going from A to B to C and possibly running back to B, you are not getting anywhere, it should be more a one stop place, possibly an umbrella of services that are specially trained to deal with not just the spouses, to deal with the children and all age groups.'

Women raised concerns that responses from medical professionals, the guards and Tusla were not always aligned, and in addition concerns were raised over a lack of access to specialist support. In two examples, women only found out about local domestic abuse support through Citizens Advice and their solicitor.

One woman posited that the solution was:

'Having people educated, it's about having our health service focussing in with specialists in the area so that when somebody presents, they get referred to specialist or referred to [name of local domestic abuse community organisation]so they get the right help at the right time' she felt this was particularly important as from her own experience, 'the wrong help is meddling and is dangerous.'

Another women highlighted that accessing support can be particularly challenging in rural communities as the lack of local supports was a huge issue:

'One of my instances happened in lockdown, I wasn't going to travel 77 kilometres to [city] hospital on my own in the middle of lockdown. If you are in a rural area there has to be some sort of, like a community guard, somebody is trained with the health system in the local garda station.'

It was noted in the group that addiction, coercive control and domestic abuse can go hand in hand but that there isn't always recognition that substance misuse can be a coping mechanism from domestic abuse. One participant highlighted how she was in recovery herself, and in the case of her friend who was murdered by her abusive partner, her needs weren't identified because

'The symptoms she was presenting with were put down to addiction and put down to her being unstable. She was doing the very bare minimum to try and block out the pain and the fear.'

Many in the group spoke about how post-separation abuse is as challenging if not worse than experiencing the initial domestic abuse. In the circumstances of post separation, the women expressed their experiences of having to deal with courts, Tusla, social welfare and guards as well as with their abusive partners and the hugely re-traumatising effect it had on them as women survivors. Several women highlighted that 'only for [local community organisation] I wouldn't be here today". They described how smaller community-based services were an important support to navigating the vast web of state services and were essential for their survival and recovery.

One woman highlighted the impact low funding for community organisations was having and how, due to limited funds, the organisation which supported her was not able to continue to work with her: 'they got me to the barring order, got me to the safety order but after that I was on my own'.

Reflecting on the discussion, the support worker who sat in as a support for the participants affirmed the stories which women shared, underlining that their experiences were sadly very common:

'Women who receive support from our service have consistently reported traumatic impact of secondary victimisation from a range of service providers including medical, Gardai, Judicial, Housing and Social Welfare. In many cases services fail to understand the dynamics of domestic abuse and often the inappropriate intervention has exposed both women and their children to further danger.

Secondary victimisation of women who experience domestic abuse has not changed in the twenty-one years of our service existence. The nature of domestic abuse which imposes shame, guilt and fear on victims/survivors and the lack of education and awareness of the issue generally mitigate against collective action and continue to make the dynamics and inappropriate responses invisible.

# NWC recommendations to improve system integration to support a victim-centred approach:

A cross Departmental approach and joint Department of Health/HSE approach is required to establish regional umbrella services for women and children experiencing domestic abuse which bring together health, justice, family support and social welfare services all under one roof.

The HSE should develop clear referral pathway into specialist local services where these exist to ensure accessible and tailored help can be provided.

Government funding must also be provided to improve access to specialised community supports for women experiencing domestic abuse, particularly in rural areas.

Sensitive routine
enquiry for domestic abuse,
including coercive control,
should be mainstreamed in
addiction services to support
early identification and
support.

The third National
Strategy on Domestic, Sexual and
Gender-Based Violence should bring
forward a whole-of Government
public health approach. This approach
necessitates outlining primary,
secondary and tertiary interventions
which mitigate diverse risk factors and
promote the safety, health and
wellbeing of all women.

#### Findings:

### Women of Minority Ethnicity



Nineteen women joined the workshop for women from minority ethnic communities. Based on the demographics survey, across the workshops, women of minority ethnicity were primarily of non-Irish Black background, or non-Irish White background, with a couple of women identifying as Asian-Irish, including Indian-Irish or as Irish Travellers. In this workshop women raised several concerns, including lack of representation in research; barriers to care; the specific discrimination that women of minority ethnicity face within the health system and accessibility and inclusion.

#### **Lack of Minority Ethnicity Representation**

For workshop participants, an initial observation was that they did not see themselves represented in the MCCP representative research which was presented at the opening of the workshop. There was a sense of weary resignation to this as women expressed a strong view that research often overlooks their particular experiences. They also highlighted that marginalisation and vulnerability can inhibit some women of colour or of migrant background speaking out about the gaps in the system out of fear this may further inhibit access to services.

There were mixed feelings in the group around the value of consultation. Some participants expressed frustration that as a marginalised community, women of minority ethnicity are often consulted yet this does not necessarily lead to change, with one woman highlighting the persistent health inequalities the Travelling community face despite ongoing engagement. Similarly, another woman voiced:

'Why do we always have to talk about our trauma in order to get something done, why is it not seen from a human perspective'. She highlighted that persistently being asked to reflect on poor experiences 'induces a trauma response'."

Another participant noted there may be helpful learnings to take forward from previous work and as such 'no need to reinvent the wheel'. 12

For other participants, the opportunity to give feedback based on their own experiences or those of their network was welcome. These participants viewed the workshop as an important space to speak openly about concerns in the hope that some progress can be made. One woman characterised the workshop as "an opportunity to give voice to the voiceless."

While issues of representation and meaningful consultation received the most discussion in the workshop, many of the points made resonated with concerns raised in the disabled women's workshop.

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<sup>11</sup> The participant was making a broad point around the role of lived experience in the policy development process. The breakout room lead facilitator, Dr. Marianne O'Shea actively listened to this, accepted the point, and reiterated that no participant should feel expected to share personal stories and we are looking at this from a human rights lens.

<sup>12</sup> Existing literature which may be helpful for the Women's Health Action Plan: Fennelly, E., Flaherty, G. (2017). 'Responding to Migrant and Refugee Healthcare Needs in Ireland', International Journal of Travel Medicine and Global Health, 5(1); Migge, B., Gilmartin M. (2011) Migrants and healthcare: investigating patient mobility among migrants in Ireland. Health Place. 17(5); Abdalla, S. et al. (2011) All-Ireland Traveller Health Study: Our Gheels; Similarly, Professor Ailish Hannigan is leading a multidisciplinary participatory health research study since 2017, see Hannigan A, Basogomba A, LeMaster J, et al (2018) Ethnic Minority Health in Ireland—Cocreating knowledge (EMH-IC): a participatory health research protocol, BMJ Open.

# NWC recommendations to support meaningful engagement in policy development:

Work with participants as equal partners, ensuring that they are kept updated and that engagement is not a one-off exercise. Before organising a new consultation be clear what the purpose of this is and what added value it can bring beyond the research that exists to date.



#### **Systemic Barriers to Care**

Several women highlighted concerns regarding the long waiting lists for access to services and the impact this can have on timely help, as well as continuity of care. The women described doctors being under significant pressure, and how this can manifest in poor experience of consultation and support: 'because of workload on them, they are too rushed'. The women expressed feelings of frustration at not having a voice in decisions around care and treatment approach, as well as concerns around the lack of join-up in support and how this made them feel like little progress is being made:

'You've been there for the last six months now you are coming back, you see a different doctor each time ... that new person is asking you the same questions you were asked six months back. This is not really reflective of a good health system.'

Women described how transition points can be particularly difficult for service navigation and support. For example, one woman raised the transition from accessing health care as a student into the general system, while an asylum-seeking woman highlighted the transition from accessing healthcare in one health region to another. This woman shared her experience that after finally securing an appointment with a psychologist, she was moved to a different direct provision centre - despite trying to delay the move to facilitate the consultation - and in her new health district she was returned to the back of the queue for mental health support.

More broadly, access and experience of mental health services was raised by the women as an area that needed additional consideration. Some participants shared difficult experiences of mental health services, one woman spoke of an experience of being sectioned which she described as traumatic for her and her children who 'may' have witnessed the events.



### Barriers specific to the intersection of ethnicity and gender

While noting that there are skilled and expert professionals in the health care system, women spoke of experiencing lack of empathy and sensitivity, and highlighted examples of bias, racism and discrimination in the health service.

'I'm white I'm Irish but I'm also a Traveller...
because of being a Traveller we have been
treated different and do face inequalities
in accessing services mainly to do with
people's prejudice. We have our rituals in
relation to births and deaths but if these
are not recognised, you are dismissed'.

From an asylum seekers perspective 'It's very difficult for us to open up about our problems, doctors are different, sometimes I had a good experience, but there were times I wouldn't ask a question because the moment they see you they treat you different and speak to you differently'.

Another woman expressed the view that 'the unconscious biases come through even in the way they speak to you, not knowing your background, not understanding the context from which you come from.'

Some of the participants described how they felt afraid to make a complaint. One Traveller woman pointed out that she encouraged a young mother to make a complaint regarding a comment made to her in hospital but the young women was afraid to do so "she said no - her fear is that she would be treated worse if she made a complaint because she hadn't had her little second baby at this stage"

With regard to asylum seekers, it was suggested that some may be afraid to complain because of their legal status "They might be afraid of not getting their papers, so they are just quiet they are not speaking out".

This is similar to a point made by another participant who reflected that even taking part in research exploring these issues induces worry: 'There is a fear element attached to it because you are so scared that somehow they are going to know that it is you and you don't want to take away from the service that you do get, you don't want to rock the boat.'

'I think there has to be a kind of cultural awareness training, because I am from another place, does not mean I do not deserve the best. We are all human beings, we should be treated equally, that duty of care has to be there.'

Multiple women described how they felt some professionals in the health system did not understand their particular needs and highlighted the need for greater understanding and training, with one woman saying:

'I think there has to be a kind of cultural awareness training, because I am from another place, does not mean I do not deserve the best. We are all human beings, we should be treated equally, that duty of care has to be there.'

While some women had good experiences of GP care, others highlighted that lack of understanding can inhibit accurate diagnosis and care, with one woman speaking about sickle cell disease and the need to improve understanding of how illnesses vary in prevalence and presentation across diverse populations.

Some women described how they felt poor experiences of care have led them to being afraid to attend appointments, while others expressed fatigue from having to fight for support and a deciding to withdraw from the system:

'It is really disheartening trying to navigate this, so much so that I refuse to see a doctor in Ireland, I haven't been back to a doctor as you just get dismissed'

Financial barriers were also raised in this workshop. Women of colour and migrant women in the workshop raised the issue that cost is a significant barrier to accessing care.

One woman in Direct Provision described the situation: 'If you are pregnant in Monaghan you have to go to Cavan to have a baby if you feel something before your due date and you have to call an ambulance you'll be told you can't just call an ambulance yet people don't have money for taxis  $\[ \in \]$ 50 for a taxi there and back. People are afraid to go to hospital because they say if I go and they discharge me how do I come back? If you are discharged at 10pm you are on your own'.

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## NWC Recommendations to address systemic barriers to care:

Ensure that unconscious bias training and cultural competency training is mandatory and training design and delivery should be coproduced with representatives from diverse minority ethnic communities.

Review undergraduate training to ensure that medics are alert to how certain health conditions may be more prevalent amongst different populations and are equipped with the skills and knowledge to identify and support service users.

Recognise the particular challenges that women in Direct Provision can face and ensure there is clear guidance in place to promote their access to timely healthcare. This should address amongst other issues, cost barriers and integrated care plans in the case of accommodation transfer.

Provide greater
education and Traveller
culture and heritage in
schools to combat ignorance
and discrimination.

#### **Accessibility and Inclusion**

All participants had some level of engagement with the health system, but often this was during a health crisis. The women in the workshop expressed concerns at the little support they experienced to navigate the healthcare system and felt that greater support would enable them to access care before needs reached crisis point.

Many women expressed concern about levels of information about, and accessibility to services, overall. Language barriers in particular were seen as a big obstacle and a lack of translation and interpreters meant that the women struggled to be heard in healthcare interactions. One woman highlighted that education and support was also important: 'we as clients, or patients, we need to be educated when you have some challenges.'

The participants also raised that their experiences of gaps in language supports had additional consequences beyond the immediate issue of their care and treatment. One woman described that the absence of medical interpreters meant that they were often reliant on informal support with communication. This reliance meant they felt a lack of privacy or ability to speak openly in care settings:

'In my community, English is not their first language, it's hard sometimes when they go to hospital because some women they need to go inside with their men, husband, boyfriend whatever, they're not, they don't have freedom to talk'.

Some women also raised that reliance on family interpretation can inhibit them being seen as individuals and that it can lead to skewed perceptions of cultural and relational dynamics. Lack of language capacity had been erroneously understood as a lack of capacity to understand their own health issues or to make informed choices about their treatment.

While language supports were the women's biggest concern, women also highlighted the issue of representation and the benefits of a shared understanding of their needs and context from the service-provider. One woman highlighted how lack of cultural awareness or sense of commonality can jeopardise experience of healthcare. As she described it can take multiple attempts before connecting with the right professional and for her: 'that someone is normally a doctor from a migrant community that is willing to assist with you as opposed to the Irish doctor who just dismisses you'.

In keeping with this need for shared understanding, the idea of earlier support in community was seen as essential, with participants highlighting the importance of working with grassroots organisations and community groups and ensuring that the migrant communities are included in all stages. 'They need to include the immigrant community when they are planning and delivering their services ... so they can raise what they are going through.'

This was reinforced by another woman: 'Know your clientele, know your serviceuser, everyone comes with their own set of cultural backgrounds ... It's not a one size fits all approach when it comes to health because health looks and feels different for so many people.'



## NWC Recommendations to Improve Accessibility and Inclusion:

Develop multi-lingual resources for women to support understanding of how the healthcare system works and what they can expect in different settings if seeking care. Review and expand current provision of interpretation services in healthcare settings to ensure optimal coverage, with a diverse range of languages catered for.

Develop primary
healthcare projects for
women from migrant
communities similar to those
developed for Travellers
and Roma.

Consider the role of peer education and how women can support other women from migrant or minority ethnicity communities.

Representation matters

– ensure that women of
minority ethnic groups are
supported to develop careers
within the health system and
progress to senior levels.

### **NWC Conclusion**

The experiences of the women in the workshops are in line with the research highlighted in the literature review of *Women's Health in Ireland* undertaken to support the Women's Health Action Plan, as well as the central concerns raised in the MCCP research regarding the dismissal of women's voices and the lack of support available to them to navigate the care pathway. That representative research highlighted that women believe their needs are being underserved in four primary ways. Through 1) a limited conversation and feeling unsupported or embarrassed 2) not being treated as an individual and feeling rushed 3) carrying the greater burden of care and financial inequality and 4) because of an out of touch system which wasn't seen to be communicating with them.

This radical listening exercise enables a greater understanding of the specific struggles marginalised women face with regard to access and experience of healthcare. From the thematic analysis, we can see that while some needs are specific to the particular context of that group of women, other needs align with, but are magnified versions of, the needs identified in the representative sample research. This suggests there needs to be focused consideration of women on the margins in all universal policy and practice development, in addition to more targeted measures to address specific challenges as outlined.

Accelerating the roll-out of Sláintecare and working to develop a universal health system based on the feminist values of solidarity, equality, inclusion and participation will be essential for addressing inequalities. As we emerge from the pandemic it is critical that we recognise the need for a restructuring of our health system towards a free at the point of access model, providing the appropriate resourcing to enhance service capacity and meet diverse needs.

As well as reimagining system design and delivery from a rights-based perspective which recognises and addresses the needs of the most vulnerable, we need to adopt a public health approach that prioritises prevention of health inequalities in the first place.

Such an approach is not only essential from a social justice perspective, but also cost effective. Early intervention through greater community and family

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supports can mitigate risk trajectories for women in the present, as well as for future generations. Experience of childhood adversity, such as abuse, neglect and family hardships significantly increase health risk behaviours, such as smoking, alcohol and drug misuse, and obesity, and is associated with multiple adverse physical and mental health conditions such as heart disease, respiratory disease, strokes, depression and anxiety in adulthood. Economic modelling of this in the British context shows that the total attributable cost to childhood adversities was estimated at £42.8 billion, with the majority of costs related to exposures to multiple rather than a single adversity, and the bulk of the costs driven by increased rates of mental illnesses and cancer. 14

Mental health was an issue which received attention across all four workshops, with the absence of appropriate mental health support having a significant impact of women's health and wellbeing. Yet the evidence is very clear that investment in mental health has significant societal benefit. Globally, is estimated that for every \$1 invested in scaled-up treatment for depression and anxiety, there is a \$4 return in better health and productivity<sup>15</sup> – and given that women<sup>16</sup> are at greater risk of these mental health conditions, a failure to invest in Ireland has profound implications for gender equality and health outcomes.

The Government's Women's Health Action Plan provides a unique and essential opportunity to rectify historical under-consideration of women's needs, and in particular, the needs of the most marginalised. It is essential that in developing this Plan we consider the evidence through an intersectional lens and adopt policy and practice recommendations that tackle inequality, mitigate risk trajectories, resist re-traumatisation, and promote the health and wellbeing of all.

'Know your clientele, know your serviceuser, everyone comes with their own set of cultural backgrounds ... It's not a one size fits all approach when it comes to health because health looks and feels different for so many people.'

<sup>13</sup> Hughes K, Bellis MA, Hardcastle KA, et al. (2017)The effect of multiple adverse childhood experiences on health: a systematic review and meta-analysis. Lancet Public Health; Centers for Disease Control and Prevention BRFSS ACE module. Available: <a href="https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/ace-brfss.html">https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/ace-brfss.html</a>

<sup>14</sup> Hughes, K., Ford, K., Kadel, R., Sharp, C. A., & Bellis, M. A. (2020). Health and financial burden of adverse childhood experiences in England and Wales: a combined primary data study of five surveys. BMJ open, 10(6), e036374. https://doi.org/10.1136/bmjopen-2019-036374

<sup>15</sup> Lancet Public Health Editorial (2020) Mental Health Matters VOLUME 8, ISSUE 11

<sup>16</sup> Albert P. R. (2015). Why is depression more prevalent in women?. Journal of psychiatry & neuroscience: JPN, 40(4); McLean, C. P., Asnaani, A., Litz, B. T., & Hofmann, S. G. (2011). Gender differences in anxiety disorders: prevalence, course of illness, comorbidity and burden of illness. Journal of psychiatric research, 45(8).

#### **Appendix A:**

## Further information on workshops



Group	Rationale for inclusion – From Women's Health in Ireland Paper	Organisations reached out to for participant recruitment
Women from Ethnic Minorities, including Migrant, Traveller and Roma women	<ul> <li>Undocumented migrants, those seeking asylum and those who have refugee status often experience poor access to health services and therefore are more likely to suffer from poorer health outcomes, face delayed access to screening, treatment and care, limited access to contraception and heightened levels of discrimination and genderbased violence.</li> <li>Traveller women have a life expectancy more than 10 years lower than the general population. Traveller and Roma women experience stark health inequalities due to structural inequalities linked to the social determinants of health and are also disproportionately impacted by poor mental health.</li> </ul>	Akidwa, Migrant Rights Centre Ireland, Immigrant Council of Ireland, Women4Women (Southside Partnership), Cairde, ENAR.  The National Traveller Women's Forum and Pavee Point were approached but declined to participate as they wanted to make a joint presentation to the Taskforce given the deplorable statistics in relation to Traveller women's health and that Traveller women cut across all of the groups being consulted in the process. The National Women's Council and Community Work Ireland respected this and relayed this to the Department of Health.

Group	Rationale for inclusion – From Women's Health in Ireland Paper	Organisations reached out to for participant recruitment
Women with experience of violence and abuse	There are many health implications for those who have experienced violence including emotional distress, transmitted infections or diseases, anxiety, depression. One in four (equivalent to 400,000 Irish women) has experienced physical and/or sexual violence since the age of 15.	Observatory on Violence Against Women, Survivors Informing Services and Institutions (SISI), Women's Aid, DRCC, Domestic Violence Response
Socio-economically disadvantaged women, including single parents	<ul> <li>Women from lower socio- economic groups who experience the greatest disadvantage in health, are at a greater risk of poor health, experience a higher burden of ill-health and live shorter lives than women from other groups.</li> <li>Women living in poverty and</li> </ul>	An Cosan, SPARK, One Family, NCCWN, Saol Project, Community Work Ireland, Merchants Quay Ireland, Dublin Inner City Community Co-op, Doras Buí, Loughrea FRC, Gort FRC, West Clare FRC
	isolation, particularly lone parents regularly highlight the impact of low income on their health.	
	86% of lone parents are women and 99% of those receiving the One Parent Family Payment are women.	
	• In August 2018 women made up 42% of the national adult homeless population (rising to 44% in Dublin), increase due to rising numbers in family homelessness, the majority of which are lone parent, female-headed households. 50% women experiencing homelessness classified their health as 'poor' or 'fair' and 90% had at least one diagnosed mental or physical health problem.	

Group	Rationale for inclusion – From Women's Health in Ireland Paper	Organisations reached out to for participant recruitment
Disabled women	<ul> <li>Of the total female population 13.8% have at least one disability</li> <li>Women with disabilities have lower uptake of health promotion and health screening services than women in general.</li> <li>Women with disabilities experience inequality in accessing sexual health services.</li> <li>Adults with disabilities are more likely to experience violence than their non-disabled peers and those with intellectual disabilities are most at risk.</li> </ul>	Disabled Women Ireland, National Deaf Women of Ireland, Mental Health Reform, Re(al) Productive Justice, AsIAm, Inclusion Ireland



#### **Workshop Format**

Topic Guide for workshop discussions

#### Immediate response to MCCP findings - 15 minutes

Problems – women in MCCP research identified following problems:

- · Limited information and conversation on women's heath
- Not treated as an individual
- Carrying the greater burden
- An out of touch system
- Lack of dignity and unfair treatment (carers)

Solutions – women in MCCP research suggested priority on:

- Make women's health part of the conversation
- Educate and inform
- Women first thinking

### Experience of healthcare system and developing an inclusive system - 30 minutes

(led by participants but if there are silences, points to enquire about)

- Access and wait-times
- Geographical locations
- Cost
- Care duties
- Nature of the consultation with medical professional
- Referrals
- Treatment and aftercare



The National Women's Council & Community Work Ireland invite you to



#### Disabled Womens' Experience of the Irish Healthcare System -A Radical Listening Workshop

Workshop Purpose - to inform the work of the Women's Health Taskforce

We know from the 'Women's Health in Ireland - Evidence Base for the development of the Women's Health Action Plan', disabled women can face particular barriers in accessing healthcare.

NWC, CWI and the Taskforce believe that it is critical that the voices of women with disability are heard in all discussions and plans in relation to women's health.

We will host a two-hour workshop to hear your views and would very much value your contribution as part of a group discussion. Our plan is to produce a report for the Women's Health Taskforce based on the workshop.

Participants will be asked to complete a short, anonymous survey during the workshop so we have basic information on participants' backgrounds.

Participation is open to anyone who identifies as a woman over the age of 18.

Please let us know if you or any members of your group would be interested in attending and if there are any particular supports you need, such as a support person to attend with you or translation or sign language, to ensure you can participate fully.

The maximum number for the workshop is 15 and we will be allocating places on a first come first served basis.

IN RECOGNITION OF THE VOLUNTARY TIME THAT PARTICIPANTS WILL BE GIVING THROUGH THEIR ATTENDANCE, A 650 ONE4ALL VOUCHER WILL BE SUPPLIED TO ALL PARTICIPANTS.

Please see attached a further letter of invitation from Rachel Kenna, Chief Nursing Officer with the Department of Health

The workshop will be held online on zoom on Monday 28th June, 2.30pm - 4.30pm Please RSVP to Rachel Doyle racheldoyle@communityworkireland.ie by Friday 18th June at 4pm. If you have any questions, you can email Rachel or call on: +353(0)87 2998619



The National Women's Council & Community Work Ireland invite you to



Women Survivors of Violence & Abuse's Experience of the Irish Healthcare System - A Radical Listening Workshop

Workshop Purpose - to inform the work of the Women's Health Taskforce. established in 2019 by the Department of Health with the aim of improving women's health outcomes and experiences of healthcare.

We know from the 'Women's Health in Ireland - Evidence Base for the development of the Women's Health Action Plan', women who are survivors of violence and abuse can face barriers in accessing healthcare

NWC, CWI and the Taskforce believe that it is critical that the voices of women survivors are heard in all discussions and plans in relation to women's health. We will host a two-hour workshop to hear your views and would very much value your contribution as part of a group discussion. Our plan is to produce a report for the Women's Health Taskforce based on the workshop.

Participants will be asked to complete a short, anonymous survey during the workshop so we have basic information on participants' backgrounds

Participation is open to anyone who identifies as a woman over the age of 18 translation or sign language, to ensure you can participate fully

first served basis.

IN RECOGNITION OF THE VOLUNTARY TIME THAT PARTICIPANTS WILL BE GIVING THROUGH THEIR ATTENDANCE, A 650 ONE4ALL VOUCHER WILL BE SUPPLIED TO ALL PARTICIPANTS.

Please see attached a further letter of invitation from Rachel Kenna, Chief Nursing Officer with the Department of Health.

The workshop will be held online on zoom on Wednesday 30th June, 10,30am – 12.30pm Please RSVP to Rachel Doyle racheldoyle@communityworkireland.ie by Friday 18th June at 4pm. If you have any questions, you can email Rachel or call on: +353(0)87 2998619



The National Women's Council & Community Work Ireland invite you to



Women from Minority Ethnic Groups' Experience of the Irish Healthcare System - A Radical Listening Workshop

Workshop Purpose - to inform the work of the Women's Health Taskforce, established in 2019 by the Department of Health with the aim of improving women's health outcomes and experiences of healthcare

We know from the 'Women's Health in Ireland - Evidence Base for the development of the Women's Health Action Plan', women from minority

NWC, CWI and the Taskforce believe that it is critical that the voices of women from minority ethnic communities are heard in all discussions and plans in relation to women's health.

We will host a two-hour workshop to hear your views and would very much value your contribution as part of a group discussion. Our plan is to produce a report for the Women's Health Taskforce based on the workshop.

Participants will be asked to complete a short, anonymous survey during the workshop so we have basic information on participants' backgrounds.

Participation is open to anyone who identifies as a woman over the age of 18.

Please let us know if you or any members of your group would be interested in attending and if there are any particular supports you need, such as a support person to attend with you or translation or sign language, to ensure you can participate fully.

IN RECOGNITION OF THE VOLUNTARY TIME THAT PARTICIPANTS WILL BE GIVING THROUGH THEIR ATTENDANCE, A 650 ONE4ALL VOUCHER WILL BE SUPPLIED TO ALL PARTICIPANTS.

Please see attached a further letter of invitation from Rachel Kenna, Chief Nursing Officer with the Department of Health.

The workshop will be held online on zoom on Tuesday 29th June, 10.30am - 12.30pm Please RSVP to Rachel Doyle racheldoyle@communityworkireland.ie by Friday 18th June at 4pm. If you have any questions, you can email Rachel or call on: +353(0)87 2998619



The National Women's Council & Community Work Ireland invite you to



Nomen Living in Disadvantaged Communities' Experience of the Irish Health Care System -A Radical Listening Workshop

Workshop Purpose - to inform the work of the Women's Health Taskforce, established in 2019 by the Department of Health with the aim of improving

We know from the 'Women's Health in Ireland - Evidence Base for the development of the Women's Health Action Plan', women from these

NWC, CWI and the Taskforce believe that it is critical that the voices of women living in socially and economically disadvantaged communities are heard in all discussions and plans in relation to women's health.

We will host a two-hour workshop to hear your views and would very much value your contribution as part of a group discussion. Our plan is to produce a report for the Women's Health Taskforce based on the workshop.

Participation is open to anyone who identifies as a woman over the age of 18.
Please let us know if you or any members of your group would be interested in attending and if there are any particular supports you need, such as a support person to attend with you or translation or sign language, to ensure you can participate fully.

IN RECOGNITION OF THE VOLUNTARY TIME THAT PARTICIPANTS WILL BE GIVING THROUGH THEIR ATTENDANCE, A 550 ONEAALL VOUCHER WILL BE SUPPLIED TO ALL PARTICIPANTS.

Please see attached a further letter of invitation from Rachel Kenna, Chief Nursing Officer with the Department of Health.

The workshop will be held online on zoom on Tuesday 29th June, 2.30pm – 4.30pm Please RSVP to Rachel Doyle racheldoyle@communityworkireland.ie by Friday 18th June at 4pm. If you have any questions, you can email Rachel or call on: +353(0)87 2998619

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