Submission to the Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities

April 2021

National Women's Council

Introduction

Founded in 1973, the National Women's Council (NWC) is the leading national women's membership organisation. We represent and derive our mandate from our membership, which includes over 190 groups and organisations from a diversity of backgrounds, sectors and locations across Ireland. Our mission is to lead and to be a catalyst for change in the achievement of equality for women. Our vision is of an Ireland and of a world where women can achieve their full potential and there is full equality for women.

We welcome the opportunity to make a submission on the initial state report under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It is the state's responsibility to take specific measures to reduce barriers to ensure disabled women can fully realise their social, cultural, political and economic rights as set out in the UNCRPD. As a matter of priority, we call on the state to ratify the optional protocol urgently. A cross sectoral approach to achieve the full implementation of the UNCRPD is required.

We have been working collectively with disabled women since March 2020, on the inclusion and visibility of disabled women across our organisation, strengthening our policy and advocacy work on health, care, violence against women, economic independence, participation and leadership. We would like to acknowledge their contributions and insights informing our submission. We are grateful for the contributions of our members National Traveller Womens Forum and Pavee Point also.

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Language

Language, and the way we use it, plays an important role in creating and maintaining discrimination or reinforcing inequality. It can also represent a statement of identity, dignity and rights. Disability refers to the social limitations and role restrictions placed on people with impairments, by their interaction with a physical and social environment, which does

not recognise their situations and their needs. The term 'woman with a disability/disabilities' may be interpreted as implying that the disability rests with the woman, whereas the term 'disabled woman' may imply that it is external circumstances that have 'disabled' her. These terms are used interchangeably among women and in the UNCRPD and for the purposes of this document we also use the terms 'women with disabilities' and 'disabled women' interchangeably. This reflects the varying perspectives in the group.

We follow the social model of disability. This focuses on the inadequacies of social, environmental, political and economic factors in society that restrict the full participation of people who have impairments thereby failing to fully accommodate their needs. This emphasis on political and economic processes that generate disabling environments draws attention to why people with disabled people experience such high levels of social exclusion and discrimination and provides us with a clear direction to achieve full and equal rights for all disabled people.

Context

Little attention has been paid to the specific experiences and needs of disabled women in Ireland. It is sometimes assumed that policies and practices are gender neutral. There is a lack of understanding of the ways in which gender and disability issues interact. Gender inequalities in the structures of our society combine with disadvantages experienced by disabled people to create particular forms of exclusion and discrimination for disabled women.

The discourse on disabled women has also often been limited to discussion of health needs, reflecting a medical model approach, rather than the right to participate in the civil, political, economic, social and cultural life of our communities and corresponding barriers to this.

We are concerned that the experiences of women are not visible within the wider response to Covid-19 and particularly women with intersecting identities. Covid 19 amplified the issues that many women, girls, non-binary, trans, and gender non-conforming persons with

disabilities experience in their everyday lives, often due to stigma, stereotypes, and discrimination at the intersection of gender and disability. For marginalised women, who already have higher mortality and morbidity rates, the collection of data and monitoring within a human rights framework is essential to protect lives and ensure equality of opportunity and outcomes in accessing public services. Many disabled women have been restricting their movements, have found access to employment and transport extremely restricted, isolated from family and friend networks and disability services including day and respite have been significantly reduced. It has been particularly challenging for people with intellectual disabilities.[1] There are significantly higher numbers of disabled women who are aged over 70.[2]. Disabled women faced the possibility of losing their support workers and personal assistance should they become ill, impacting on their independence and quality of life.

Intersectionality

The narrative around disabled women can be very one-dimensional and an intersectional approach is required. It is important to note that disabled women are not a homogenous group. They have many different identities, among them, women from a migrant background, ethnic minority women, LGBTQI, women seeking international protection and Traveller women for example a deaf woman from a migrant background might require specific interpretation services when accessing public services.

Research has indicated that Travellers are more likely to experience disability than the general population, almost 1 in 5 Travellers categorised as having a disability.[3] This impacts on access to services and employment.[4] Disabled Travellers share the concerns of the broader disabled community as well as concerns specific to their experience as disabled Travellers, such as isolation from and within their own community, a lack of recognition of Traveller identity, inappropriate and inadequate service provision, inappropriate and inadequate accommodation and racism and discrimination, as well as identifying the almost

[1] NESC(2021) Secretariat Covid-19 Working Paper Series Gender and Covid-19 in Ireland
[2] CSO (2016a), Census of Population 2016 – Profile 9 Health, Disability and Carers, Central Statistics Office. https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9d/, 04/02/2021.
[3] CSO(2016
[4] ESRI(2017)

complete dearth of information on the numbers and specific experience, particularly access and outcome from service provision of disabled Travellers. It is important that national and international policy and human rights legislation is inclusive of and responsive to the diverse needs and identities of disabled Travellers and addresses structural inequalities using an intersectional approach in order for social justice and equality of access, participation and outcome to be achieved for disabled Travellers.

Responding to the needs of disabled Travellers should not take place solely within the context of a health model. While the health needs and status of disabled Travellers, along with the health needs and status of all Travellers, must be improved and specifically addressed, for disabled Travellers this must be within the context of a rights based, person centred, social model of disability.

Gender, ethnicity and disability proofing

There is a lack of gender, ethnicity and disability disaggregated data to inform policy and decision making and make visible the experiences of disabled women for example on poverty, participation in public and political life and gender-based violence. All strategies and policies relevant to the lives of disabled women must be gender, ethnicity and disability proofed. We need gender and equality disaggregated data to better understand the lives of all disabled women. Data disaggregated across all equality grounds would give more visibility to diversity and intersectional issues. The needs of disabled women are no less significant than those of the rest of the disabled community or women, but disabled women encounter and experience a wide range of barriers across a number of areas. Disabled women can feel absent or invisible from the spaces and places where decisions are made about their lives.

The State report notes the establishment of an expert Equality Budgeting Expert Advisory Group, of which NWC is a member. Despite this progress, there continues to be a lack of gender and disability proofing across key policy and budgetary developments. For example, there has been little attention to the needs of disabled women in proposed pension reforms or in the Roadmap for Social Inclusion.

It is the view of NWC, that efforts to ensure policy is gender and disability proofed would be supported by implementing legislation to put gender and equality budgeting on a statutory footing.

RECOMMENDATIONS

- Publish a gender and equality impact statement with the annual budget with disaggregated data on disabled women
- All future legislation drafted in any of the policy areas mentioned under the UN CRPD should undergo mandatory disability and gender equality proofing.
- Develop legislation to put gender and equality budgeting on a statutory footing
- Establish a training fund for resources and staffing to support:

- Cross dept. training on gender budgeting implementation

- Development of disaggregated data collection and analysis

- Provide funding to support NWC & other civil society organisations as recommended by the OECD and UN

Violence against women: Article 16

Article 16 of the UNCRPD requires the State to put in place measures to protect disabled women from violence. Disabled women activists and writers have identified a number of factors which have contributed to making them more vulnerable to violence. These centre on the non-recognition or non-acceptance of the same rights for a disabled person as for the rest of the population; male values, attitudes and behaviours; and a 'devaluing' of disabled women. Compounding this is the way disabled people are portrayed, as vulnerable beings easily under control. Discrimination and social prejudice are perhaps the most pervasive contributor to violence against women with disabilities (NDA, 2004).

A systematic review of evidence by the WHO[5] shows that children and adults with disabilities are more likely to experience violence than their non-disabled peers and those

[5] Hughes K., Bellis M., Jones L, Wood S, Bates G, Eckley L, McCoy E, Mikton C, Shakespeare T, Officer A. (2012). 'Prevalence and risk of violence against adults. Prevalence and risk of violence against children with disabilities: a systematic review and metaanalysis of observational studies.' The Lancet. 379(9826):1621-9. Retrieved from: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61851-5/fulltext

with intellectual disabilities are most at risk. Disabled women are not visible in the wider response to violence against women. Disaggregated data on disabled women does not always exist, but the following statistics highlight disabled women's increased vulnerability to violence. The Fundamental Rights Agency in an EU-wide survey in 2014, found that 34% of women with a health problem or disability have experienced physical or sexual partner violence, compared with 19% of women who do not have a health problem or disability.[6] Recent research from NUI Galway found 40% of disabled female students reporting experience of rape (compared with 27% of non-disabled students).[7]

Disabled women are likely to be trapped in a violent relationship longer than non-disabled women and in some instances such violence can lead to acquiring an impairment. Male violence and sexual violence towards women over a number of years can and does cause physical impairments as well as long-term mental health issues. For example, deafness can often be the result of being beaten on the head or mental health difficulties the result of systematic bullying and verbal abuse (NDA, 2004).

Coercive control was criminalised in Ireland in 2018 through the Criminal Law (Domestic Violence) Act. The Section 39 of the Act is confined to intimate partner/former relationships. This is extremely limited and does not cover the coercive controlling behaviour that some disabled women experience from carers, relatives or friends who may exploit the disabled women's vulnerability. There are calls in the UK to expand the coercive control offence to include other close adult relationships, recognising that beyond intimate partner relationships, this insidious harm is perpetuated. As such, all victims of coercive control need to be protected by the law.[8]

People with intellectual disabilities face a five times increased risk of forced marriage compared to those who are non-disabled.[9] While evidence suggests that forced marriage

[6] Fundamental Rights Agency, 'Violence against women: an EU-wide survey', 2014.
[7] https://www.nuigalway.ie/media/smartconsent/Sexual-Experiences-Survey-2020.pdf
[8] https://www.gov.uk/government/news/new-laws-to-protect-victims-added-to-domestic-abuse-bill
[9] Clawson, Patterson, Fyson, & McCarthy, 2020

may be equally likely to affect men or women with learning disabilities[10] , the consequences of forced marriage on disabled women may differ to that of men. Recognised consequences of forced marriage include domestic abuse, sexual abuse and domestic servitude. The intersection between gender, disability and forced marriage needs to be better understood and integrated into State action and policy responses.

The systematic abuse of women within State institutions has been chronicled in several state reports/commissions. The most recent of these the Mother and Baby Home Commission addressed disabled women and their children, and concluded that: "physical and intellectual disabilities did affect the outcome for some children, but there appears to have been no systematic or large-scale discrimination in either Pelletstown or Bessborough". This does not seem to accord with the evidence presented to the Commission and misses completely the voice of disabled women as evidenced by the final paragraph of Chapter 13 which reads: "It is notable that no submissions were made to the commission either by individuals or groups on the issue of disability or mental illness in the homes so the voice of those affected residents has not been heard". The distinct absence of the voice of disabled women is extremely concerning as it is unlikely, if not impossible, for such women to be included in the reparation they are entitled to.

There needs to be more resources to ensure access to support for disabled women across the country, if they are experiencing intimate partner abuse and violence. It is vital that they know that supports exist and that their safety is paramount particularly during this public health crisis. For example, Gardai being able to communicate with a deaf woman experiencing intimate partner violence and being able to communicate with that women prior to the hearing partner would be vital. Alongside this, disabled survivors of abuse should be involved in designing better support and accessible awareness raising messages, for example more visibility of disabled women in the "no more excuses" campaigns.

We know home is not a safe place for many women. For many disabled women, where they live and who they live with is not their choice. The segregated living situations can

[10] Foreign & Commonwealth Office and Home Office, 2018

compound the situation and also isolate disabled women from mainstream supports. Vulnerability is compounded where disabled women are economically dependent on their partners or surviving on inadequate social welfare payments. We need to better understand the dynamics of intra familial abuse and institutional abuse and ensure that legislation adequately protects all women. Disabled women living in congregated or institutional settings or with families may find accessing specialist support agencies difficult due to a lack of privacy or access to assistive devices or assistive technology devices. The Second National Strategy on Domestic Sexual and Gender-based Violence 2016-2021 has no targeted interventions with disabled women. We urgently need consistent and quality data on disabled women's experiences of gender and sexual based violence.

RECOMMENDATIONS

- Systematic gathering of data on disabled women's experiences of domestic, sexual and gender-based violence needs to be a priority for all state bodies and agencies.
- Publicly funded awareness campaigns on the issue of violence against disabled women need to be run. Disabled women should also be visible in all public campaigns around domestic, sexual and gender-based violence.
- Recognise the commonality amongst all women who experience violence, while also being aware of the specific experience of women disabled women who have been subjected to violence and abuse.
- Increased resourcing of domestic violence service providers to ensure they can develop appropriate services, including outreach services, aimed at disabled women.

- Recognise and fund appropriate helpline services for disabled women (for example using texting and email for women who are deaf or hard of hearing).

- Ensure that all information about support services is accessible and available to disabled women who experience violence and abuse. Information and other materials made available in accessible formats, for example, Braille, large print and on audio tape.

- Recognise the right of disabled women to access mainstream services addressing violence and abuse.
- Resource free and confidential access to an independent advocacy and legal advice for disabled women who experience domestic, sexual and gender-based violence.

- Disabled women should be consulted as to what response is needed to address violence against disabled women and in developing good practice guidelines.
- Support the empowerment of disabled women of all ages to make safe and informed choices about their relationships and sexuality.
- Legislative reform is needed to expand the offence of coercive control to include other close adult relationships.
- Greater understanding of the link between gender, forced marriage and intellectual disabilities needs to be undertaken. This intersectional understanding needs to be integrated into the government response to forced marriage.

Economic inequality: Article 27 and 28

Ireland has the lowest rate of employment among disabled people in the EU.[11] Disabled people experience multiple barriers to employment including lack of workplace flexibility, cost of disability and additional long-term healthcare costs, discrimination and negative attitudes and stereotypes. For disabled women, these barriers interact with gender inequalities to create further barriers to work.

Childcare remains one of the key barriers to women's participation in the labour market. While 63.7% of disabled women are mothers, there has been little focus on the needs of disabled women with caring roles. The barriers disabled women experience result in lower labour force participation rates, with a participation rate of 26% among disabled women in 2016, compared 35% for disabled men. Despite this, there is no reference to women or actions aimed at supporting disabled women in the Comprehensive Employment Strategy for People with Disabilities nor is there any reference to the need for childcare to support disabled women's labour market participation.

A survey of Disability Allowance recipients by the Department of Employment Affairs and Social Protection found that 43% of those not at work expressed the desire to work part

[11] Department of Enterprise, Trade and Employment (2021) Making Remote Work: National Remote Work Strategy

time or full time.[12] Of those currently working part time, 26% said they would like to increase their hours. Flexible hours were cited by 30% of respondents as the most important factor in helping them achieve their employment ambitions and goals. While the development of Ireland's first national remote work strategy has the potential to support disabled women to find and retain employment, it is important that remote and flexible working is led by the disabled worker and that it is not used to replace the responsibility of employers to create more accessible workplaces.

The gender pay gap in Ireland is 14.4%, with women more likely to work in low paid and minimum wage jobs. However, there is no pay data available in Ireland on the experiences of disabled women. Research from the UK indicates that the pay gap for disabled women is nearly 9% higher than that experienced by the overall population of women. However, disabled and non-disabled women were both paid less than disabled and non-disabled men. The largest gap found is that between disabled women and non-disabled men, with non-disabled men being paid 36% more than disabled women.[13]

The social welfare system plays an important role in reducing poverty and inequality. It should ensure that everyone, no matter what their stage of life, can live free from poverty. However, disabled people experience unacceptably high levels of poverty, with 38% of disabled people at risk of poverty, three times that of the general population in 2019. With 18% of disabled people living in consistent poverty in 2019, the State has much work to do to ensure that the national poverty target of 2% consistent poverty is met.[14] Across the EU, disabled women are more likely to experience poverty than disabled men. However, there are no specific targets in the Roadmap for Social Inclusion for addressing the high levels of poverty experienced by disabled women or disabled people overall.

These measurements of poverty, while already unacceptably high, do not take into account the additional costs disabled people must pay to achieve the same standard of living as non-

[12] DSP (2016). Department of Social Protection Report on Disability Allowance Survey. https://www.welfare.ie/en/downloads/DSPReportonDisabilityAllowanceSurvey2015.pdf
[13] Trades Union Congress (2020). Disability pay and employment gaps. UK: TUC
[14] CSO (2020). SILC 2019

disabled people, for example, additional utilities costs, specialised clothing or footwear or extra taxi journeys necessitated by a lack of accessible public transport. Research has estimated the cost of disability at between 35% and 55% of income or between €207-€276 per week for the average disabled household with variation according to the person's support needs.[15] Disabled women are disproportionately affected by cost of disability as they make up a larger number of those over 55 and research has found that cost of disability impacts most acutely on older, disabled people.[16]

According to research by the ESRI, "policies that reduce poverty among the general population do not adequately address deprivation experienced by vulnerable groups" and targeted interventions are needed to support disabled people. The State must implement a cost of disability payment as a matter of priority.[17]

With pensions tied to labour market participation, economic inequalities experienced by disabled women are built up over a lifetime and reinforced in our pensions system. Women are less likely to have occupational pensions and more likely to be reliant on non-contributory state pensions which are means tested and lower than contributory pensions. Though there is no publicly available gender and disability disaggregated data on pensions, given their low labour market participation rates, it is probable that this pattern also applies to disabled women.

RECOMMENDATION

- Increase social welfare payments so that they provide a minimum essential standard of living (MESL)
- Set ambitious poverty reduction targets for disabled people as part of the Roadmap for Social Inclusion
- Collect and publish gender and disability disaggregated data on poverty

[15] Cullinan, J. & Lyons, S. (2015). The private economic costs of adult disability. In Cullinan, Lyons & Nolan, the economics of disability. Manchester: Manchester University Press
[16] Cullinan, J. (2014). The Economic Cost of Disability for Older People. https://www.nuigalway.ie/media/researchsub-sites/healtheconomics/files/HEPA-Bulletin-2014-No.-1.pdf
[17] ESRI (2018). Poverty dynamics of social risk groups in the EU: an analysis of the EU Statistics on Income and Living Conditions, 2005 to 2014

- Deliver a non-means tested cost of disability payment to address the extra costs experienced by disabled people
- Address low pay by increasing the minimum wage to the living wage
- Deliver a public model of childcare so that childcare is accessible and affordable for disabled women
- Monitor implementation of the remote working strategy to ensure it works well for disabled women

- collect gender and disability disaggregated data on its implementation

- Ensure that remote working is always optional with the worker having the right to refuse remote working.

- Make disabled women visible in the Comprehensive Employment Strategy and resource measures to support disabled women's participation in the labour force

Supports to live independently: Article 19

Discussions about gender, disability and care have often focused on women as carers and disabled people as care recipients while overlooking the reciprocal nature of care as well as the care roles carried out by disabled women. They are often engaged in advocating for themselves and their family members to secure their rights.

NWC acknowledges that disabled people are not passive recipients of care but individuals whose rights are intertwined with those, predominantly women, that provide care. Positioning disabled women as dependents or passive recipients of care ignores the personhood of disabled women. Our feminist analysis of care includes not only the perspectives of the women who provide care but also the women who need such supports.[18]

Historically, disabled people were institutionalised in large campus style settings where they lived and accessed health, social and other services. It is now well recognised that these institutions were both a form of human rights abuse in and of themselves, as well as a

[18] McDonagh, R. https://www.irishtimes.com/life-and-style/health-family/disabled-people-have-been-made-to-believe-they-are-the-problem-1.3774721

perpetrator of human rights abuses.[19] However, the absence of a sufficient state response to supporting disabled people to live independent, supported lives forces disabled people into a position of dependence on family members, most often women.

Despite a wealth of policies[20] committed to providing person centred, community-based supports to enable disabled people to live independent lives in their communities, 56% of adults with intellectual disabilities were living with family members and only 6% living independently in 2017.[21]

The State has continued to fall behind in its commitments to implement 'A Time to Move on from Congregated Settings' and full implementation of this policy must be a priority. However, a range of state supports such as accessible and culturally appropriate housing, accommodation and transport, personal assistance services, sign language interpretation, are required to support disabled women to live autonomous lives.

NWC supports the call of disabled persons organisations and disability activists for legislation to guarantee disabled people the right to a Personal Assistance Service, as a key mechanism to deliver on Art 19. Personal Assistance is distinct from Home Help and Home Care and is seen as a necessary self-directed support to reduce dependence on family and friends and to maintain a private life with dignity.[22]

RECOMMENDATION

- Develop and invest in universal social care services for disabled people across the lifespan so that people can live autonomous lives in the way they want to
- Increase funding for personal assistant services
- Resource the implementation of the Irish Sign Language Act 201

[19] For example, McCoy report on Aras Attracta, HSE's Time to Move on from Congregated settings, UN Committee on the Rights of Persons with Disabilities General Comment on Article 19 of the UNCRPD.
[20] DOH's Value For Money and Policy Review of Disability Services (2012), HSE's Time to Move on from Congregated settings, National Disability Strategy, National Housing Strategy for People with Disabilities, National Disability Inclusion Strategy to name a few.
[21] Health Research Board (2018). Report of the National Intellectual Disability Database 2017
[22] Independent Living Movement Ireland (2019). Independent Living Movement Ireland (2019). ILMI Personal Assistance Services Campaign

- Fully implement the 'Time to Move on from Congregated Settings' policy by allocating sufficient resources to transition remaining residents to community settings with the required supports
- Increase public and affordable housing by delivering up to 100,000 new homes on public land over five years.

Effective access to justice: Article 12 & 13

The Assisted Decision Making (Capacity) Act was passed into law in 2015. The Act recognises that all people have equal legal rights, and reinforces the right of everyone to make choices in line with their own will and preference. It also sets out a framework for supporting people who may experience challenges with making decisions. Many of the substantive provisions of the Assisted Decision-Making Act 2015 have not been commenced, including a legal framework for Advance Healthcare Directives and the main support structure it provides for – the Decision Support Service – has yet to open. Full commencement of the Act and the provision of adequate resources for its implementation is essential for Ireland to become compliant with the UNCRPD.

The figures for disabled people in prisons in Ireland are proportionately higher than for the rest of the population, in particular for prisoners with psychosocial and intellectual disabilities. An estimated 85% of women in prison have addictions, and 97% of women in the Dóchas Centre are on prescription medication. There is a very high prevalence of mental illness, disability, self-harm, and experiences of trauma, sexual violence, domestic violence, and childhood sexual abuse among women in prison.[23]

Further, the lack of appropriate supports and access to healthcare may induce a person may develop a disability within prison due to lack of appropriate support and access to healthcare. The European Court of Human Rights has found that the lack of physical

[23] State must stop using prison to fill gaps in care for women and girls on the margins'. Available at https://www.iprt.ie/iprt-in-the-news/oped-state-must-stop-using-prison-to-fill-gaps-in-care-for-women-and-girls-on-the-margins/

accessibility or a restricted access to appropriate health care constitutes a violation of the prohibition of torture.[24]

Studies on the conditions of detention of prisoners with disabilities show that prisoners with physical disabilities often have to rely on peers to shower, use the restroom or move around prison, exposing them to a risk of violence and dependence. Prisoners with disabilities are also exposed to a higher risk of physical, emotional and sexual violence, particularly women prisoners with disabilities.[25] While similar environmental accessibility issues were identified in the female and male prison settings included in this research, some gender-based differences in prison design or environments were noted by particular stakeholders.[26]

NWC welcomes the undertaking by the Government to develop the first ever Strategy for the Criminal Justice System. Effective multi-agency coordination and collaboration is particularly important for supporting disabled women, including those with mental health issues, who are engaging with the criminal justice system. Our system must be able to meet a diverse range of needs, including communication or healthcare needs.[27] It is also to be welcomed that the Justice Minister has brought a memo to Cabinet to establish the task force to consider the mental health and addiction challenges of people in prison.[28]

RECOMMENDATION

- Provide the additional funding required to ensure that the Decision Support Service opens as a matter of urgency
- Deliver on the legislative actions needed for full commencement of the Assisted Decision-Making Capacity Act
- Continue to focus on distinct gender-specific responses to women in the justice system.

[24] Article 3 European Convention on Human Rights in cases such as Semikhvostov v Russia and Murray v The Netherlands.
[25] Irish Penal Reform Trust 'Making Rights Real for People with Disabilities in Detention'. Available at https://www.iprt.ie/latest-news/guest-article-making-rights-real-for-people-with-disabilities-in-detention/
[26] 'Out of the Shadows': Women with learning disabilities and the criminal justice system. Available at https://www.iprt.ie/international-news/out-of-the-shadows-women-with-learning-disabilities-and-the-criminal-justice-system/
[27] Speech by Minister of State James Browne T.D at the National Disability Authority Annual Conference 2020. Available at http://www.justice.ie/en/JELR/Pages/SP20000244
[28] https://www.oireachtas.ie/en/debates/debate/select_committee_on_justice/2021-03-30/8/

Health: Article 12, 14 & 25

Health is a product of the conditions in which women are born, grow, live, work and age and it is a resource enabling us to live well. Disabled women experience a high level of unemployment and consequently are more likely to be living on low incomes. This in turn means they are more reliant on public health services which means they have long waits. Although women have a higher life expectancy than men, women spend many more years than men living with age related ill-health and disability.[29] Due to accessibility issues and lack of universal design in mainstream services, disabled women may experience poorer access to health and social care services.

Barriers for disabled women in accessing and using health services include: accessibility in health services; location of services; difficulties in transport and moving around the physical environment; difficulties relating to orientation in health care settings; lack of provision of suitable health information; difficulties with communication; lack of knowledge and negative attitudes and behaviours from staff; and failure of healthcare professionals in recognising and appreciating disabled women's needs.

Disabled women experience barriers to accessing health screening services resulting in lower uptake of breast and cervical cancer screening, especially low for women more complex support needs. [30] It is the responsibility of health care providers to ensure that disabled women can access this care. A disabled woman may not be able to get on to an examination table and it is up to doctors to have other more accessible equipment so that all women can receive necessary healthcare. To access breast check a hoist maybe required, it is not always clear that this will be available. Some wheelchairs used by disabled women depending on size, weight and adaptability means they can use the mammogram machine. Often the ability of disabled women to access these essential services will depend on

[29] Department of Health. (2016). Health in Ireland Key Trends 2016. Retrieved from: https://health.gov.ie/wp-content/uploads/2016/12/Health-in-Ireland-Key-Trends-2016.pdf

[30] Burke, E., McCallion, E., McCarron, M. (Eds.) (2014). Advancing years, Different challenges: Wave 2 IDS-TILDA: findings on the ageing of people with an intellectual disability: an intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: Trinity College Dublin. Retrieved from: https://www.tcd.ie/tcaid/assets/pdf/Wave_2_Report_October_2014.pdf

accessible transport, allocation of sufficient personal assistance hours or the provision of appropriate ISL interpretation. In addition to physical and information access issues, attitudes also have significant impact. For example, the Cervical Check Women's Charter informs disabled service users: "If you have special needs and require assistance in accessing the programme, Cervical Check will support you". Disabled women do not have 'special' needs they have specific access needs.

A whole-of-life approach to healthcare services; women and other gender minorities are far more likely to remain undiagnosed or to face excessively delayed diagnosis when compared with cis men, particularly for conditions which are more commonly associated with women. There is a large gender difference in the age of diagnosis, with many women not diagnosed until adulthood in the areas of autism,[31] ADHD[32] and Ehlers-Danlos Syndrome.[33]

Mental health

Depression is the leading cause of disability worldwide and women are disproportionately impacted by depression. Both poverty and social exclusion are key determinants of mental illness and almost 50% of women with disabilities in Ireland are at risk of poverty or social exclusion.[34] Disabled women are less likely to be employed, with family caring responsibilities a key reason for their lower rates of employment,[35] this has an impact on their mental health and how the access the mental health services with caring responsibilities being a specific need. The mental health impacts of violence are far reaching and are well documented in research. Aligned to this, there is robust evidence that children and adults with an intellectual disability are at a higher risk of sexual abuse than

[31] Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. Journal of the American Academy of Child & Adolescent Psychiatry. 2017 https://doi.org/10.1016/j.jaac.2017.03.013. [PubMed]
[32] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195638/
[33] Demmler, J. C., Atkinson, M. D., Reinhold, E. J., Choy, E., Lyons, R. A., & Brophy, S. T. (2019). Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case-control comparison. BMJ open, 9(11), e031365. https://doi.org/10.1136/bmjopen-2019-031365
[34] European Institute for Gender Equality. (2016). Poverty, gender and intersecting inequalities in the EU Review of the implementation of Area A: Women and Poverty of the Beijing Platform for Action. Brussels: EIGE
[35] Watson, D. & Nolan, B. (2011). The Social Portrait of People with Disabilities in Ireland 2011. A report by the Department of Social Protection and the ESRI. Dublin: DSP

nondisabled peers, and the mental health needs arising from this experience of abuse are varied,[36] underlying the importance of adopting person-centred and trauma-informed models of care in health systems and structures. Disabled women also experience significant barriers in accessing mental health services. The suicide rate is six times higher for Traveller women than the general population. For deaf and hard of hearing women the cost of sign language interpretation is not covered when they access mental health services in the private sector. There is a disproportionate number of women in prison experiencing mental health difficulties.[37]

RECOMMENDATION

- Develop gender sensitive and accessible health services that are delivered with dignity - sensitive to the diversity of disabled women's needs, experiences and backgrounds including ethnicity, sexuality and disability.
- Embed trauma-informed principles across health and social care services and ensure there are tailored clinical support pathways for disabled women and girls who have experienced abuse.
- Collect qualitative and quantitative data to enable future planning of diagnostic and screening services so that they are more accessible and inclusive including Breast Check and Cervical Check

Relationships, sexual and reproductive healthcare and justice: Article 23 & 25

One way in which women's equality is realised is through women's control of their reproductive and maternal health. This is why reproductive health has been a core area of NWC's work for many years advocating for quality, universal, lifelong reproductive healthcare for women and girls. We are closely involved in improving women's access to contraception, increasing maternity entitlements, advocating for affordable, quality childcare and for the ongoing development of women-centred maternity care. NWC advocates for reproductive healthcare services which are based on best medical practice

[36] Byrne G. Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. Journal of Intellectual Disabilities. 2018;22(3):294-310. doi:10.1177/1744629517698844

[37] https://www.iprt.ie/site/assets/files/6332/iprt_position_paper_on_women_in_the_criminal_justice_system.pdf

and which reflect the lived experiences of women. Health policies and services must reflect the diversity of experiences women face and the different decisions women make about reproduction and family formation. Reproductive justice is the ability to make decisions, and have choices respected, around becoming a parent or not. This includes fertility, contraception – including assisted human reproduction, abortion, pregnancy, birth and parenting – including fostering and adoption. Disabled women face additional barriers such as physical inaccessibility of services, societal attitudes that deny their sexual and reproductive agency and a hesitancy among service providers to provide adequate information and services.[38]

Due to a legacy of institutionalisation and segregation, women and girls have been deprived of information and education on sexuality and family planning and experience a historic and contemporary use of long-term contraceptives without informed consent. Disabled girls and women can face additional barriers in accessing sexual health and relationships education. For too long disabled women have been entirely discounted as sexual beings, neglected from sex education, subject to safeguarding to prevent sexual activity, which undermined their human right to sexual expression. Disabled women face unique difficulties in accessing and utilising contraception. A woman's living environment was shown to affect contraceptive use. Living in an institution was associated with using contraception, particularly institutions where sexual relationships were not prohibited and where contraceptive use was required or advised.[39] The state must respect the rights of disabled women to make reproductive decisions and provide appropriate support to enable choice and informed decision making.

63.7% of disabled women are mothers however they are not mentioned in our current maternity strategy.[40] They are likely to experience negative perceptions around being or becoming a mother. Disabled women are more likely to experience poverty and this can

[38] Grant, S (2017) 'Sexual and reproductive healthcare issues facing women with disabilities' http://frontlineireland.com/sexual-reproductive-healthcare-issues-facing-women-disabilities/
[39] http://nda.ie/nda-files/People-with-Intellectual-Disability-Crisis-Pregnancy-Report-Summary.pdf
[40] HSE(2016) Creating a better future together National Maternity Strategy 2016 – 2026 https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf

have negative repercussions on their choice to become a parent. [41]Some are parenting alone, cohabiting, divorced, widowed and in same sex relationships. There is a need to increase awareness about the varied birth experiences of disabled women, including those of women who are neurodiverse. Disabled women are more likely to have children taken into care, particularly women with intellectual disabilities[42] without sufficient parenting supports being offered first and despite consistent evidence that maternal IQ is not systematically correlated with parenting competence. Professional support and family and social support are strongly correlated to parenting success as opposed to level of intellectual disability. There are increased interventions, judgement, scrutiny and monitoring of disabled parents that is disproportionate to non-disabled parents; and a lack of uniformity about the use and quality of parental capacity assessments. The national model of parenting services must consider support for disabled parents not just parents of children with additional needs.[43]

There are barriers and issues to disabled women accessing termination of pregnancy services – such as the accessibility of services (3 day wait and 12 week cut off) and information and a lack of decision making supports for women with intellectual disabilities. There is also a gap in data about the provision of reproductive services to disabled people, particularly with the new framework for abortion services. Geographic coverage is still not being provided more than two years after the law was introduced. Only ten of all the country's maternity hospitals offer terminations up to twelve weeks.[44] During the Covid19 pandemic, Ireland introduced remote access to early abortion care in line with public health guidance on restricting social contact. There is a robust body of international peer-reviewed research confirming that this is a safe and effective approach to health care that is highly acceptable to women who require abortion.[45] This model of care has the potential to increase accessibility of the service and broaden its reach and may be particularly beneficial

[41] CSO (2020). SILC 2019
[42] https://www.childlawproject.ie/wp-content/uploads/2015/11/CCLRP-Full-final-report_FINAL2.pdf
[43] https://www.gov.ie/en/consultation/1b75c-public-consultation-on-the-development-of-a-national-model-of-parenting-support-services/
[44] https://www.irishexaminer.com/news/arid-40250726.html
[45] M. Endler, A. Lavelanet, A. Cleeve, B. Ganatra, R. Gomperts, K. Gemzell-Danielssona "Telemedicine for medical abortion: a systematic review" BJOG: An International Journal of Obstetrics and Gynaecology. 126 (9) 2019: 1194-1102. https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.15684

for disabled women and those with underlying health conditions who have restricted movement. As we emerge from this pandemic, it is vital that a blended model of care is made available, ensuring that service users who prefer remote consultation continue to have that option going forward. Delays in the full realisation of the UNCRPD and the current legal capacity framework contributes to violations in the lives of disabled women and going forward, it is vital that we develop our health policy in line with UNCRPD guidance to enable full inclusivity.

NWC supports legal regulation of assisted human reproduction (AHR) services to safeguard the interests of women, couples, children and healthcare professionals and to provide equitable access and the best standard of care to those who require it. Concerns have been expressed about the general scheme of current assisted human reproduction bill and the lack of engagement in the pre-legislative scrutiny by disabled women. This must be rectified before the Bill progresses any further

RECOMMENDATION

- The national model of parenting services must consider support for disabled parents not just parents of children with additional needs.
- Establish a court support office which could appoint and oversee independent advocates for disabled parents in childcare cases.
- Provide for age appropriate, inclusive, objective, accessible, comprehensive sexual health and relationship education within and outside the formal education system
- Information on sexual health and reproductive healthcare must be accessible including provision of Irish sign language interpretation
- Ensure that contraceptive options laid out under draft plans to introduce free contraception meet the health requirements of disabled women and include contraception decision making
- Ensure the review of the Health (Regulation of Termination of Pregnancy) Act 2018 fully decriminalises abortion and removes ongoing obstacles to disabled women's access to abortion services, including reviewing criteria in the Act.

- Engage with the Re(al) Productive Justice project to understand the real-life experiences of disabled people in Ireland in making reproductive decisions.
- Meaningfully address the absence of disabled people's voices and experiences from pre-legislative scrutiny of the Assisted Human Reproduction Bill 2017.
  - Ensure the Ethics Committee of the AHR Regulatory Authority, when established, includes the voice of disabled people.
- Provide continued access to remote early abortion care post-Covid19 in cases where it is clinically appropriate and the preference of the service-user.

Participation in public and political life – Article 29

Women still represent a small minority of elected representatives and political decision-makers everywhere. In Ireland, only 22.5% of TDs are women and 25% of councillors are women. The barriers for women's participation in politics are encapsulated in the "5 C's"[46] and an additional 6th C, Cyber Violence;

- ✓ Cash – women earn, on average, 14% less than men, so have less resources to deploy in expensive election campaigns
- ✓ Care – women do the overwhelming majority of care and domestic work leaving less leisure time to build the essential networks and relationships
- ✓ Confidence – acutely conscious of the maleness of the system women sometimes do not put themselves forward but prefer to be asked to run for election
- ✓ Candidate selection – political parties are the gatekeepers and tend towards selecting male candidates
- ✓ Culture – the male-designed and dominated culture is off-putting to many women
- ✓ Cyber Violence - Women politicians experience a high degree of threats of physical and sexual violence online.[47] This can be particularly acute and hostile for minority women candidates and younger women.

[46] Report on women's participation in politics (2009). Joint Committee on Justice, Equality, Defence and Women's Rights. http://www.oireachtas.ie/documents/committees30thdail/j-justiceedwr/reports_2008/20091105.pdf

[47] https://www.amnesty.org/en/latest/research/2018/03/online-violence-against-women-chapter-3/

Disabled women are a diverse group who experience various degrees of discrimination and face many systemic barriers to the exercise of their political rights and empowerment because of their gender and disability. These barriers can be of legal, physical, and attitudinal nature, and include an inadequate access to education, health care, employment, and justice. Disabled women are still not included in the decision-making processes, policy making and political structures of government at national, regional or local level. We do not have an identified disabled women representative in the Oireachtas and only one disabled women councillor in Local Government and one member of the European Parliament.

Data on the political participation of disabled women is scarce. Everyone has the right to take part in government and public affairs, to vote, and to be elected. It the opportunity to be involved in political life, whether by standing for elected office, electing a candidate, joining a political party, listening to or participating in a political debate or even reading political news stories in the media is at the heart of what it means to live in a democratic society. The accessibility audits of polling stations that have been carried out and the provision of an accessible ballot paper for blind and visually impaired people is very welcome. However, engagement must be broader than just voting at elections. Disabled women should be supported to engage in participatory democracy and this is a matter for civil society organisations, political parties, and government. Positive action measures are required to ensure disabled women are on State boards, at senior levels of the Civil Service, in national delegations abroad, in local elections, and their participation in regional and local public decision-making forums.

Diversity in representation matters. It is often those who are furthest away from power - Traveller and Roma women, working class women, disabled women, migrant women and carers – who experience the impact of policy making the most. Disabled women are organising and working together through Disabled People's Organisations (DPO's) such as Disabled Women Ireland and informally. A DPO is an independent membership organisation, run by and for, disabled people. This work needs to be meaningfully resourced and practically supported, if we are serious about increasing disabled women's participation

at all levels of society. Many disabled women are carrying out unpaid work in campaigning and championing disabled people's rights. Often disabled women will have to make stark choices when it comes to community participation and engagement, when personal assistance hours and services are limited and have to be prioritised to support basic needs.

Representation of women from organizations of persons with disabilities tends also to be low in national coordination mechanisms on disability matters" and their representation "in national machinery for gender equality is even lower."[48] Allowing more flexibility in the way national and local government operates long-term would open the doors to a more diverse range of people who want to take an active part in our political life. Arcane and anti-social parliamentary working practices, as well as the glacially slow recognition of the need for maternity and parental leave, remain major barriers to women's involvement in political life. Deaf and hard of hearing women who wish to take part in a political campaign or to become a councillor, need access to funding for ISL interpretation costs. Women do the overwhelming majority of care and domestic work leaving less leisure time to build the essential networks and relationships necessary to break into the political sphere. The male designed and dominated culture is off-putting to many. Without direct intervention – including quotas, targets, greater flexible practices, the collection of intersectional data and improved reporting – progress will remain far too slow.

Political parties are the gatekeepers to women's political participation.[49] They can do more to support the engagement of disabled women in their membership and to run for office including outreach, accessible membership forms and collecting data on membership. Practical supports and resources are required to enable a run for office. Particular resources are necessary to mediate access for disabled women and women from minority backgrounds including financial and canvassing support.[50] The personal is political for disabled women campaigners and activists and those who have run have been motivated by

[48] Realization of the Sustainable Development Goals by, for and with Person with Disabilities, UN Flagship Report on Disability and Development 2018
[49] https://www.osce.org/odihr/414344
[50] Women For Election (2021) *More Women – Changing the Face of Politics*, Dr Fiona Buckley & Dr Lisa Keenan https://womenforelection.ie/wp-content/uploads/2021/03/WFE-More-Women-Changing-the-Face-of-Politics.pdf

their own life experiences.[51] Scotland has established an Access to Elected Office Fund which provides financial support to candidates with disabilities.[52] In 2015, the Scottish government commissioned Inclusion Scotland to develop a program called Access to Politics, which proactively reaches out to disabled people who might be looking for greater involvement in political life, and offers non-financial advice to those involved in politics at any level. This includes individual goal setting, encouragement, networking and advice on the rights and adjustments that some organizations, including political parties, should make to ensure equal access. Targeted training, mentoring and other initiatives to support disabled women's participation/uptake in political structures is required such as developing a network of supports for disabled women candidates or a shadowing initiative similar to the scheme organised by the Immigrant Council of Ireland.

Under-representation of disabled women in the activities and decision-making structures of women's organisations is also of concern, because it is at this level that many women begin to become involved in training, community development activity, representation and leadership. Disabled women must be supported and resourced to engage proactively in emerging issues around a just transition and climate action. Specific engagement must take place with disabled Traveller and Roma women, and this engagement should be developed and designed alongside Traveller and Roma organisations in addition to the participation of Traveller and Roma representatives on formal decision-making structures.

Using the Taoiseach's nominee to increase diversity within the Seanad is welcome but we need broader reform including universal access to the franchise to elect members of the Seanad. Quotas and designated seats represent only one part of the solution, to a complex issue of women's participation in public life more broadly. Politics needs to be a place where disabled women feel welcome. Public bodies within the state must be cognisant of their obligations from the Public Sector Duty[53] to prioritise the most marginalised and vulnerable in society and to ensure that women enjoy equality with men in political and public life.

[51] ibid
[52] Disability Inclusion Checklist for Political Parties https://www.osce.org/odihr/473754
Guidelines on Promoting the Political Participation of Persons with Disabilities
https://tandis.odihr.pl/bitstream/20.500.12389/22513/2/22513_EN.pdf
[53] https://www.ihrec.ie/our-work/public-sector-duty/

RECOMMENDATION

- Investment into women's community sector to resource meaningful participation and engagement of disabled women.
- Full and prioritised engagement with Disabled Persons' Organisations, including the provision of adequate funding and capacity building supports on a local and national level.
- It is crucial that the Taoiseach's nominees to the Seanad are all women, or majority women, and that the all nominees reflect the diversity in our society.
- Women's organisations and other appropriate civil society organisations (such as those related advocacy and support in areas such as race, ethnicity, LGBTQIA+ support etc.) should also be able to draw down funding for activities related to making their services more accessible, to ensure that disabled women can participate equally in all aspects of their identities.
- Remove the intersectional barriers to women's political participation including an access to elected office fund to cover transport, ISL or other access costs.
- Resource women's organisations and DPOs to support them to build the capacity of disabled women including financial support, mentoring programmes, ISL access
- Strengthen linkages between the disability and women's movement to directly engage with disabled women in decision making.
- Continue to facilitate remote and hybrid practices at all levels for political participation
- Legislate for a candidate selection quota system to be extended to local elections with an initial quota of 40% women's representation in the Local Elections 2024

-Set additional targets to improve diversity including a targeted geographical strategy to address all constituencies

Conclusion

The state must seek the input of Disabled People's Organisations, including disabled women's organisations, in all policies that impact disabled women. We need a cultural shift in how society views disabled women so that their rights fully realised. It must ensure that the needs, priorities, and voices of disabled women are actively considered and supported at all level the; local, regional and national.

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