

Opening Statement to the Joint Oireachtas Committee on Gender Equality

**to discuss the Recommendations of the Citizens' Assembly
regarding Care (Recommendations 4-12) and Social Protection
(Recommendations 13-19)**

Disabled Women Ireland

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Introduction:

Disabled Women Ireland (DWI) is the national Disabled Person's Organisation (DPO) representing self-identified disabled women, girls, non-binary and gender non-conforming people in Ireland. Our members self-identify as disabled and we understand disability as a broad concept which includes physical, sensory, mental and intellectual impairments. DWI is an all-island organisation, with members located across 24 counties, living in both urban and rural areas.

Disabled Women Ireland welcomes the opportunity to present today on the recommendations of the Citizens' Assembly on Gender Equality.

We broadly support the recommendations of the Citizens Assembly and seek to ensure that actions based on them are constructed in such a way as to not further disadvantage disabled women and to uphold the rights recognised in the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

While we use the word "women" throughout our Opening Statement, this is only because data on gendered experiences of disability is lacking, and we don't have figures regarding the experiences of other gender minority groupings, but we strongly support the Assembly's statement in their open letter that "*Trans and non-binary people suffer from particular facets of inequality*". At a time where trans people's rights are facing unprecedented pushback we want to reiterate that non-binary identities are valid, trans women are women, trans rights are human rights and any deviation from that position fails to acknowledge our equal dignity as humans. Disabled Women Ireland is nothing without our trans members. We should not have to say this, but the current climate is such that we can not speak on a feminist, equal future for Ireland without doing so. In our experience, any issue which disproportionately impacts on disabled women also impacts on other disabled gender minority people to at least the same degree, and often to a greater degree.

Care (Recommendations 4-12)

Overall we support the Recommendations made by the Citizen's Assembly in relation to care, but wish to highlight a number of points essential to their being implemented in a manner which recognises the significant proportion of disabled people who are carers and which ensures that the rights and agency of all disabled people is respected. We agree with the Assembly's statement that we need to "*transform our models of care to ensure that our society values every person*" but caution that specific measures must be identified and incorporated into any implementation to both respect disabled people's autonomy and ensure that they can access any supports needed to meaningfully exercise that autonomy.

In Ireland, 67% of disabled women are parents and disabled people are almost three times more likely to be carers than non-disabled people; 45% of family carers in Ireland are themselves disabled¹. Disabled people, and in particular disabled women, are responsible for a huge portion of caring work in Ireland. We need to acknowledge this and ensure that they

¹ *The State of Caring 2020*, report by Family Carers Ireland (2020), p.16:
<https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf>

are better supported in this vital work. It is also important to acknowledge and respect the interdependence of care; care is rarely a one-way street, and the systems that we create need to reflect this.

When non-disabled people speak about care, it can often be in a paternalistic way that fails to consider that they themselves receive care support from those around them or that fails to recognise that disabled people are often givers, and not only recipients, of care. For those of us who have relied on care or have provided care, we know that these depictions of a one way model of care are inaccurate.

We support the Assembly's Recommendation that respite provision for carers should be improved but it is essential that we do not frame disabled people as burdens, a framing that plays a significant role in our dehumanisation. Indeed, disabled people themselves may also need a break from their families or careers and should be offered the opportunity to have alternative experiences, build their own social networks and spend time away from their home environments.

We want to be clear that we don't want to see increased respite provision which results in disabled people being placed in institutions, but instead the expansion of such services in ways that include alternatives to respite care for those who want them. We need to be creative and flexible in creating models that work for people on an individual basis, and some alternatives to institutional respite have already been used in Ireland. Family home-sharing and providing respite budgets directly to families have, in the past, enabled disabled people and their families to create systems which work for them. Better provision of in-home supports will make flexible, individualised alternatives much more possible and allow more freedom of choice.

We do not fully support the language of Recommendation 10, which focuses on choice of care and support. Rather than fully acknowledging disabled people's right to choose their care or support arrangements, with the individual's will and preference at the centre of all such arrangements, the language used in the Recommendation undermines the idea of equality for disabled people. To say that disabled people should be able to "*participate as fully as possible*" in decisions about their own lives reflects neither the spirit nor the letter of the UNCRPD - specifically Articles 12 and 19.

- Article 12 requires that disabled people enjoy legal capacity on the same basis as others and that they can access the support they need in exercising their legal capacity. This means that disabled people are entitled to make decisions about their own lives, and should be provided with any support they need to make these decisions.
- Article 19 states that disabled people are entitled to choose their place of residence and should have access to a range of support services of their choosing so as to enable them to live independently and be included in their communities on an equal basis with others.

As the CRPD Committee describes in the General Comment on independent living;

"Living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control

over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living.”

We are clear that Support or care without choice is neither support nor care. Support cannot be imposed upon a person. We are clear that Institutionalisation can happen in the home or in the community when the autonomy, will and preference of a person is not respected.

We agree that all people should have a statutory right to home care, but believe that this does not go far enough. All people should have a right not only to home care, but also to Personal Assistance Services and non-traditional models of home care. This is a cross cutting issue, which particularly impacts older disabled women.

A key distinction between Home Care and Personal Assistance Services, is that Personal Assistance Services empower the person receiving care to decide and direct their own support in every aspect of their lives, in line with their will and preferences, while home care services are usually offered by a service provider on a ‘take it or leave it’ basis and are limited to areas such as bathing, dressing or food preparation. As noted by the UN CRPD Committee in their General Comment on Article 19:

“Even if the responsibilities of “the employer” are contracted out, [Such as they are in home care services] the person with disability must always remain at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected.”²

This is not the model we follow with home care in Ireland.

Ahead of the Irish Government's first State Report on the UN CRPD, DWI held member consultations to discuss issues of importance in implementing the UN CRPD. An issue which was consistently highlighted by our members concerned the challenges associated with transitioning between childhood and adult disability supports but also transitioning out of all disability supports when a person reaches 65 years of age. At this point, a person transfers into old age services. Therefore, while we agree with Recommendation 12 that lifelong care for people with disabilities should be seamless and there should be no break in services or need to reapply for support, we are disappointed that this Recommendation does not recognise the experience of older disabled people. We hope that in the implementation of this Recommendation, due consideration is given to community based disability support for the over-65s.

² General comment on article 19: Living independently and being included in the community, Committee on the Rights of Persons with Disabilities (Aug 2017). Ref: CRPD/C/18/1

Social protection (Recommendations 13-19)

For disabled people, particularly disabled gender minority people, poverty is a major barrier to realising an independent and adequate standard of living. The costs of disability can be significant, and insufficient support is available to meet them while avenues to employment are restricted or closed off to disabled people. As a result, disabled women and gender minority people living in Ireland are exposed to high levels of deprivation and social exclusion, even more so than disabled men. Disabled people are twice as likely as non-disabled people to live in, or be at risk of living in, poverty and disabled women are 25% more likely to live in poverty than disabled men³.

Social welfare payments available to disabled people include Disability Allowance, Invalidity Pension and Blind Pension. The maximum payments on these allowances is €208 per week (€10,556 per annum) which is intended to cover the living expenses of disabled people who are unable to work. In addition to paying for the basics of day-to-day living, these payments are also intended to cover any additional disability-related costs disabled people incur.

Indecon's recently published "*Cost of Disability*" Report established that the average yearly cost of disability in Ireland is €11,734 and that this cost rises with the number of impairments or conditions an individual experiences⁴. This indicates that the disability-related social welfare payments available are wholly insufficient to allow disabled people and their families to reach even a minimum standard of living. Work-related income disregards, which begin to impact on disability supports even before a person's overall income has reached that of a worker on minimum wage, contribute to the long-term poverty experienced by many disabled women.

It is for these reasons that we broadly support the Assembly's Recommendations in relation to Social Protection. We believe it is absolutely essential that we adopt a fully individualised social protection system and that social protection payments and supports should be set at a level that lifts people above the poverty line, prevents deprivation and supports an adequate standard of living. We also support the Assembly's Recommendations in relation to pensions and a Universal Basic Income. We, however, would like to state that we are disappointed that the Recommendations do not include a specific reference to the cost of disability or a reflection on how means-testing of disability supports places recipients in a dependent position within families.

We also wish to highlight the interaction between financial independence and gender-based violence for disabled women and gender minorities. As stated by the Assembly in their Open Letter "*There is no place in our society for gender-based violence*". According to an Irish report, disabled women are, on average, almost 3 times as likely to be subjected to intimate violence as non-disabled women⁵. The reasons for this encompass societal attitudes and

³ Central Statistics Office (CSO), *Survey on Income and Living Conditions (SILC) 2017*: <https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2017/povertyanddeprivation/>

⁴ *The Cost of Disability in Ireland*, Indecon International Research Economists Report (Dec 2021). <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>

⁵ *Domestic Violence and abuse against people with disabilities*, Paper by the National Disability Authority to Joint Oireachtas Committee on Justice, Defence and Equality (May 2013)

perceptions of vulnerability but a core foundation, highlighted by our member's consultations and backed up by international research, is disabled women's lack of financial independence. Lack of financial independence has been found to be one of the most significant risk factors in being exposed to intimate partner violence for all women⁶. Financial dependence is also the most common barrier to escaping an abusive relationship⁷.

We can't tackle the overwhelming levels of violence directed towards disabled women without tackling the root causes like financial dependence, housing insecurity, institutionalisation and social inequality.

We are encouraged to see that within the recommendations produced by the Citizen's Assembly in relation to care and social protection, there is no suggestion of measures which disempower or deliberately uproot the lives of disabled women and gender minorities in the name of safety. When abuse is directed at disabled gender minority people, we are often met with "Safeguarding" responses that remove us from our communities, disempower us and ultimately fail to protect us. As calls for increased safeguarding powers grow louder we want to be clear that they will not protect us.

We need to examine both the causative and protective factors relating to the violence disabled women and gender minorities are subjected to - just as we do for their non-disabled peers - in order to substantially address and reduce this violence. Approaches which rely on a "safeguarding" approach fail to look past assumptions about our inherent vulnerability to the reality of our lives, and risk restricting or denying our human rights, including our equal right to autonomy, in the name of 'keeping us safe'.

We are encouraged by the steps taken by this Committee to prioritise the voices and views of disabled people and their representative Disabled Persons' Organisations on all issues which impact our lives, as required by the UNCRPD, and hope that this marks the beginning of a fruitful and ongoing conversation between the Committee members and DPOs which ensures that no-one is left behind when implementing the Recommendations of the Citizen's Assembly and that respect, dignity and equality for all remain at the heart of our work.

We look forward to today's conversation and welcome the questions of Committee members.

<https://nda.ie/nda-files/paper-by-the-national-disability-authority-to-joint-oireachtas-committee-on-justice-defence-and-equality-may-20131.pdf>

⁶ *Three Ways Domestic Violence Victims Can Overcome Economic Dependence*, Dr. A. Stylianou, Safe Horizons (2016): <https://www.safehorizon.org/news-from-the-field/three-ways-domestic-violence-victims-can-overcome-economic-dependence/>

⁷ *Cross-national and multilevel correlates of partner violence: an analysis of data from population-based surveys*, L.L. Heise & A. Kotsadam, *The Lancet Global Health* (2015); [https://doi.org/10.1016/S2214-109X\(15\)00013-3](https://doi.org/10.1016/S2214-109X(15)00013-3)