

Submission on the Mid-Term Review of the Roadmap for Social Inclusion 2020-2025

“Removing barriers to social inclusion and financial independence for disabled people”

Disabled Women Ireland

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Boxed quotations throughout the submission are from our membership consultations on the UN CRPD in March 2021. Over three days we held 20 focussed consultations on people's lived experiences of specific Articles of the Convention with 57 participants, some of whom attended multiple sessions.

Introduction

Disabled Women Ireland would like the issues raised in this submission (originally created at the request of the Joint Oireachtas Committee on Disability Matters on the topic of “ensuring independent and adequate standard of living and social protection for people with disabilities”) to inform the Mid-Term Review of the Roadmap to Social Inclusion, as this public consultation process was not communicated to us preventing us from having sufficient time to draft a more tailored submission. The issues highlighted in this submission relate across the high-level Roadmap Goals, and most directly to **Goals 1, 3 and 5**.

Disabled Women Ireland (DWI) is the only national disabled person's organisation (DPO) representing disabled women and non-binary people in Ireland. DWI is a cross-impairment and all island organisation, with members located across 25 counties North and South, living in both urban and rural areas.



Map of DWI membership by county

Specific prioritisation of DPOs representing women and girls on all national policies affecting our lives is required under CRPD Committee General Comment 7, which outlines State parties' obligations in upholding Articles 4(3) and 33(3) of the UN CRPD. This State duty “to ensure the participation of women with disabilities... as a prerequisite in the design, implementation and monitoring of all measures that have an impact on their lives” is in recognition of the fact that gender-minority people experience greater levels of impoverishment, marginalisation and social exclusion of than their peers, and requires that the specific factors underlying their increased experience of marginalisation be fully incorporated into all National Strategies and other State policies from the design and consultation stages onwards.

For disabled people, particularly disabled gender minority people, poverty and financial dependency is a major barrier to social inclusion. DWI therefore strongly urge you to give the issues highlighted in this submission their due weight and full consideration in your work on the Mid-Term Review of the Roadmap for Social Inclusion 2022-2025.

Note: Although we don't have space to explore it in this submission, we also urge examination of Family Caregiver's experiences of social exclusion and support the removal means testing from Carers Allowance and related supports as disabled people and their families' welfare is interlinked and the significant additional costs of disability usually impact families and households as a whole. Moreover, many disabled women and gender minorities are the providers of care within their families.

1. State supports' impact disabled people's standard of living and social exclusion

Disability-related social welfare payments and supports are part of the social safety net, intended to ensure that each individual enjoys a minimum standard of living and social protection from deprivation. However, not only have current allowances failed to keep pace with the rate of cost of living in general, they have not been informed by the actual costs of disability from their inception and so leave a significant proportion of disabled people below the poverty line, at high risk of social exclusion and unable to afford basic necessities.

“The cost of disability is the extra income required by disabled people to bring their standard of living up to the same level as that of other people”

National Disability Authority¹

(1.1) Social welfare payments available to disabled people include Disability Allowance, Invalidity Pension and Blind Pension. The maximum payments on these allowances average €208 per week (€10,556 per annum) and are intended to cover the living expenses of disabled people who are unable to work. Currently, minimum wage in Ireland stands at €366 per week (€19,014 per annum), meaning that disabled people in Ireland are expected to achieve a reasonable standard of living on just 55% of the national minimum wage.

(1.2) During the Covid crisis, the Government took the position that €350 per week was the minimum payment required to maintain a minimum standard of living for a non-disabled person in setting the Pandemic Unemployment Payment rate, however disabled people - with demonstrably higher costs of living - are unable to earn €350 p/w without losing access to disability supports due to means testing.

(1.3) 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 €11,734². Prima facie, this indicates that the disability-related social welfare payments available are wholly insufficient to allow disabled people and their families to reach a minimum standard of living. The increases proposed in Budget 2022 will therefore fall far short of addressing the endemic rates of poverty and social exclusion experienced by the disabled community if no further action is taken to ensure adequate social protections.

(1.4) As disabled people are unable to cover the average cost of their disability, even at the maximum rate of disability-related social welfare supports, the majority are left dependent on the good will of family and friends, going without basic life necessities such as heating and nutritious food, and unable to participate in social or cultural events, travel or engage in public life. This undermines disabled people's ability to realise a range of rights under the CRPD and confines us to lives of precarity on the fringes of society.

¹ Methodologies for Estimating the Cost of Disability', National Disability Authority (2020):: <https://nda.ie/Publications/Social-Welfare/Cost-of-Living/Methodologies-for-Estimating-the-Cost-of-Disability.html>

² The Cost of Disability in Ireland', Indecon Research Report (2021), p.21

2. Cost of Disability implications for the adequacy of social welfare supports

(2.1) The 2021 Indecon Report on the Cost of Disability also shows that the cost of disability rises with the number of impairments or conditions an individual experiences. However, this is not taken into consideration in the current operation of the Disability Allowance and other disability-related supports which assess only how a diagnosis prevents an individual from taking up paid employment, not the impact or costs associated with their impairments or conditions.³

(2.2) 2017 CSO figures show that 45.9% of disabled people experience deprivation and 24% live in consistent poverty (in comparison with 6.7% of the rest of the population).⁴ What the CSO figures don't explore is that disabled people's risk of poverty is not reduced by paid employment at the same rate as non-disabled people's.⁵ This is due to the ever-present nature of the Cost of Disability which is not currently considered in the administration of social welfare supports. Increased access to employment for those who can work, while extremely important, should therefore not be viewed as a 'silver bullet' to eradicate the high rate of poverty experienced by disabled people and needs to be accompanied by a reevaluation of social supports.

(2.3) It also should be noted that the Central Statistics Office suggests a poverty line of 60% of median national income. As of 2021, the relative income poverty line in Ireland is €286.48 for a single adult.⁶ It should be noted that the poverty rate used by the CSO in estimating rates of poverty in Ireland does not take into account the differences in standards of living experienced by similar-income households with or without a disabled member, meaning that the statistics available on poverty and disability in Ireland provide only part of the true picture of deprivation amongst the disabled community.⁷

(2.4) A simple increase in disability payments to this €286.48 median income level would therefore be insufficient to tackle poverty and social exclusion in line with the CRPD, instead policymakers should take a blended approach, informed by DPOs and other experts, to both increase social protection payments to reasonable levels and to remove existing barriers to disabled people's financial independence and inclusion in the workforce.

(2.5) The costs of disability are life-long, and may rise and need for support increases,⁸ however Disability Allowance is capped at State Pension age. This leaves older disabled people at extreme risk of poverty and deprivation. In addition, an older disabled person's specific support needs can be erased by their re-categorisation into a homogenous 'older persons' category. Research undertaken by NUIG suggests that poverty amongst disabled people is significantly underestimated as currently methodologies categorise people as either disabled or over 66 years of age, but not both.⁹ Again, the solution lies in recognising that disability supports, such as Disability Allowance, should not be administered as a replacement source of income but rather as a means to offset costs and ensure a minimum standard of living for disabled people throughout their lives.

³ Operational Guidelines: Disability Allowance', Dept. of Social Protection (2020): <https://www.gov.ie/en/publication/c075c7-operational-guidelines-disability-allowance/>

⁴ Central Statistics Office (CSO), Survey on Income and Living Conditions (SILC) 2017: <https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2017/povertyanddeprivation/>

⁵ Poverty, Disability, and Employment: Global Perspectives From the National Centre for Promotion of Employment for Disabled People', J. Abidi & D. Sharma, (2014): <https://doi.org/10.1177/2165143413520180>

⁶ Central Statistics Office (CSO), Survey on Income and Living Conditions Explained (2017)

⁷ 'The costs of disability in Australia: a hybrid panel-data examination':

https://click.endnote.com/viewer?doi=10.1186%2Fs13561-020-00264-1&token=WzEyOTU5ODYsIjEwLjE6%ODYvczEzNTYxLTAyMC0wMDI2NC0xI0.Hi_ShXms8xfAKk1sIXz0LZKC7xc

⁸ Prof. Sophie Mitra et al.: <https://theconversation.com/the-hidden-extra-costs-of-living-with-a-disability-78001>

⁹ 'The Economic Cost of Disability for Older People', J. Cullinan, Health Economics & Policy Analysis Research Bulletin Series No.1, NUIG (2014): <https://www.nuigalway.ie/media/researchsub-sites/healththeconomics/files/HEPA-Bulletin-2014-No.-1.pdf>

(2.6) The ESRI report *'Poverty, Income Inequality And Living Standards In Ireland'* found that poverty amongst people aged 65+ increased rapidly when pension was no longer benchmarked against median incomes, but also came down rapidly when readjusted against median incomes.¹⁰ Disability payments and supports need to be similarly benchmarked to tackle the high rates of deprivation and poverty experienced by disabled people in Ireland.

3. Means testing supports undermines dignity, independence and autonomy

From our consultations, we are aware that there is considerable fear and worry around losing access to Disability Allowance or related supports amongst the disabled community, which creates a background pattern of stress and insecurity in disabled people's day-to-day lives. The process of applying for means tested disability-related supports is widely viewed as distressing, complicated and dehumanising, as not only do you have to 'prove' your impairment, you also have to demonstrate how it restricts you from engaging in paid employment and provide evidence of your financial need.

"[I've had a] disability since birth. Other payments like Child Support or the Widow's Pension are not means tested, you know, so I think that should apply. You don't ever [lose] your disability.... I don't know why that can't be applied to people with disability. So I guess, these concepts exist within the structure. Why they're not applied to people with disabilities, I don't understand that. It's wrong. It's a human rights violation."

(3.1) In 2020, an already stressful and uncertain year for everyone, 63.6% of Disability Allowance refusals were overturned on appeal, either in whole or in part.¹¹ This indicates a lack of consistency in the ways in which means testing criteria are applied and cases evaluated on an individual level, which is borne out in disabled people's frequent accounts of the social welfare system being unclear, frightening and adversarial.

(3.2) While Disability Allowance and associated payments are insufficient in covering the Cost of Disability and the costs of daily living, they provide disabled people with a consistent source of income on which many of us are completely reliant. Most members at our consultations on Article 27 of the CRPD spoke about their desire to take up part-time work, to become self-employed, or to take up intermittent paid opportunities and how they are prevented from doing so by fear of losing their Disability Allowance. In addition, taking up self-employment or intermittent work also creates a substantial administrative burden on disabled people, as highlighted by the Disabled Artists and Disabled Academics (DADA) Campaign's Witness presentation to the Oireachtas.¹²

(3.3) Means testing of disability payments and supports undermines disabled people's choice and control over their own lives as well as their ability to self-direct the support and expenditure they need in alignment with their will and preferences. Means testing may also restrict their ability to choose where and with whom to live, as support is tied to the person(s) an applicant lives with.

¹⁰ Poverty, income inequality and living standards in Ireland' -B. Roantree et al, Economic & Social Research Institute (2021), p.15:

https://www.esri.ie/system/files/publications/BKMNEXT412_1.pdf

¹¹ Minister of Social Protection's response to PQ [14331/21] on 24th May 2021: <https://www.oireachtas.ie/en/debates/question/2021-03-24/973/>

¹² Emilie Conway (DADA Campaign), Opening Statement to the Joint Oireachtas Committee on Disability Matters, 7th October 2021:

https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/submissions/2021/2021-10-07_opening-statement-emilie-conway-founder-and-creator-disabled-artists-and-disabled-academics_en.pdf

(3.4) Means testing of disability supports has an immeasurable impact on disabled people's interpersonal, familial and romantic relationships; it is difficult to establish or maintain relationships of equality when you are the *de facto* dependent of your partner, sibling or parent. Financial independence has been shown to be one of the elements crucial to achieving gender equality,¹³ and it is no less crucial to disabled gender minorities.

(3.5) Due to the costs associated with disability and fewer employment options, disabled people face additional barriers in achieving financial security. This, in turn, makes it more difficult to make meaningful long-term decisions about our lives. As reductions in disability supports begin once we earn more than €140 per week, it is incredibly difficult for disabled people to establish financial security. We may have access to the support we need to live in our communities while we are unemployed, but we lose these supports once we take up employment and before we are earning enough to afford to replace these support with privately funded alternatives.

(3.6) The current system also unduly impacts those who acquire disability; because supports are means tested, people who acquire disability may have to experience loss of their standard of living or, in some cases, their home before they are 'poor enough' to access support. Instead of driving people into poverty, an approach which provides support based on need rather than pre-existing means would uphold the individual's autonomy while likely reducing overall reliance on State assistance. The administrative savings to the Exchequer of removing means testing assessments from disability-related payments and supports are likely to be significant.

"If people cannot participate in society because of additional costs associated with disability, they may also be excluded from taking a real part in the democratic processes of society or from exercising their legal rights." Citizens Information Board¹⁴

"I am an adult and still living with my parents - which is not what my peer group, the kids that I grew up with, are doing - [because] I absolutely cannot rely, long-term, on any kind of support from the Government... I'm still having difficulty with [maintaining] a healthy, clean environment and being able to feed myself because I 100% know I cannot long term rely on the government to assist me with those two things. Being able to earn enough to be able to provide those services while not working myself to a fatigue level where I can't maintain working [is] a balancing act, which is why I still live with my parents."

(3.7) Predicating access to disability payments and supports on significant lack of means is a factor in disabled people's widespread experiences of dependence and isolation which could otherwise be avoided. For example, most disabled people find that their needs will fluctuate over the course of their lifetime; rather than being able to earn a supplementary income by which they can finance additional supports independently - such as working part-time to pay for adaptations or personal assistance services which allow them to stay in their own homes - they find themselves trapped in a zero sum game

¹³ Financial independence can empower women everywhere', Bobbi Gray, Irish Independent (8th March 2018):

<https://www.irishexaminer.com/opinion/commentanalysis/and-30831400.html>

¹⁴ 'Submission to Indecon Report on the Cost of Disability', Citizens Information Board (2020):

https://www.citizensinformationboard.ie/downloads/social_policy/submissions2019/submission_on_cost_of_Disability_Research_Aug_2019.docx

whereby attempts to be as independent as they're able are penalised by immediate withdrawal of State support. This in turn may force them to either give up independence in order to guarantee access to social protection supports or to give up State supports for a position of precarity; in either case, the individual's ability to fully and equally participate in all aspects of life and to experience a reasonable standard of living is restricted by State policies.

How can we align Ireland's social welfare framework with the goals of the UN CRPD?

(3.8) Disabled people's full participation in cultural, political, public life and ability to choose where and with whom to live cannot be attained without addressing the endemic rates of poverty they experience; poverty, in and of itself, is a huge barrier to equality. To this end, Disability Allowance (and related payments and supports) should not be viewed as a means testable source of income but rather as a means by which to address the significant inequality disabled people encounter in their day-to-day lives; a way to 'level the playing field' and offset the expense associated with being disabled in a largely inaccessible society.

4. Employment barriers created by the Irish framework for social protection

4. i. Private or public sector employment

Ireland has the lowest employment rate of disabled people in the EU, at 32.3%. Ireland also has the largest employment gap for disabled people versus overall labour market employment: disabled people are 42.1 percentage points less likely to be employed than non-disabled people.¹⁵ A 2017 ESRI report found that, were Irish Government policies to better facilitate employment through the removal of practical barriers such as means testing of disability-related supports, an additional 35,600 disabled people would be enabled to join the workforce.¹⁶

"I think the disability payments system stops people from participating in work. At the moment, if you're on certain disability payments you're not allowed to [work] without losing part of your disability [payment]. People are relying on that as kind of their baseline.. It's very difficult for people. We have the lowest participation rates in the workforce in the OECD countries. I do think we need to first of all, take away those barriers that people face. The disability pay benefit system shouldn't deter people from entering the workforce... it's hugely, hugely disabling ...You still have the disability even if you return to work on some sort of part-time or temporary basis. You should continue to have [Disability Allowance]. You still have the cost of your illness, your disabilities, you should be able to continue to work without losing that."

¹⁵ 'Poverty and Social Exclusion of Persons with Disabilities', European Human Rights Report Issue 4, European Disability Forum (2020), p.48: https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF_HR_Report_final_tagged_interactive_v2_accessible.pdf

¹⁶ 'Employment transitions among people with a disability in Ireland: an analysis of the Quarterly National Household Survey, 2010-2015', D. Watson et al, The Economic and Social Research Institute (ESRI), (2017): <https://doi.org/10.26504/rs58.pdf>

(4.1) Disabled people can be caught in a ‘Catch 22’ situation, where supports they may currently be able to access, such as Personal Assistance Services, enable them to take up paid employment but they risk losing this support should they work full-time and may therefore be unable to keep up employment, falling back into a cycle of unemployment and poverty. Some may face an additional risk of losing their Medical Card, and associated healthcare supports needed to maintain quality of life, should they take up paid employment.

“I can't even take casual or temporary employment without losing half of my [Disability Allowance]. I need that money to pay for medications and my baseline needs. I don't know, my health is so precarious. It's crazy. It's all so disabling.”

4. ii. Self employment:

Self-employment is viewed by many disabled people who *can* work to be the best and most sustainable form of employment for their needs: it is more likely to offer the flexibility needed to be sustainable while managing fluctuating health needs, the disabled person is more likely to have control over their own accessibility requirements and reasonable accommodations and they do not have to navigate systemic issues of stigma and discrimination present in recruitment processes.¹⁷ Self employment schemes which specifically address the needs of disabled individual have great potential to address Ireland’s poor rate of employment amongst disabled people, however there are a number of social protection barriers which must first be addressed:

(4.3) Loss of disability supports through means testing places a self-employed disabled person at an immediate competitive disadvantage compared to their abled-bodied peers due to the significant cost of disability, even for those deemed to have ‘low support needs’.

(4.4) Means testing also means that it is difficult for a disabled person to put together the capital required to start a business; gifts or investment from friends or family may jeopardise their social protection payment and someone in receipt of a disability payment is less likely to be viewed as a viable candidate for a business loan by a bank or other commercial lending institute.

(4.5) Disabled people must cover the cost of disability - demonstrated to be an average of €11,734 per year by the recent Indecon report¹⁸ - as well as the same overheads and materials costs as their abled-bodied competitors, in order to start generating an income from self-employment. However, reductions in disability supports begin immediately once a week’s takings exceed €140. This model of means testing is not compatible with the fluctuating nature of income associated with self-employment or starting a business.

(4.6) There is no pathway by which disabled self-employed people can apply for funding for reasonable accommodations or assistive technology related to work which, again, places them at a financial disadvantage due to their disability. Changing disability payments and supports to a non-means tested model would go some way to addressing this barrier while a specific self-employment strategy for disabled people is implemented.

¹⁷ Discrimination in recruitment', F. McGinnity et al, Economic & Social Research Institute (2021): <https://www.lenus.ie/handle/10147/76641>

¹⁸ Cost of Disability in Ireland Report, Indecon (2021): <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>

*“[There is] this guy called [redacted], who's sort of peddling this idea of self employment for people with disabilities, but he is just making money out of saying here's the training results. And I'm like, without actually dealing with the whole structure of the social welfare system ...it's really disruptive, because it's basically almost sending a message that all we need is **another** training course to get out there. I'm like we've all done the training courses. That's not the point. It's that the social welfare infrastructure is prohibitive. It's destructive.”*

5. Impact of means testing payments on housing and security of tenure

As we know has been raised by multiple Witnesses the Committee has invited, there are significant issues caused by how the current allowances and housing adaptation grants are geared towards property ownership and fail to support the many disabled people trying to access the private rental market. Disabled people are at least as affected by the ongoing housing crisis and the escalating costs of private rental, if not more so. We shall therefore look at some impacts a means tested payment has on both home ownership and tenancy.

5. i. Home ownership:

(5.1) The limited capital disregard associated with a below poverty level means tested payment practically nullifies disabled people's ability to accrue capital to pay for large expenditures such as increasing accessibility of their home, saving a deposit for a house, purchasing costly accessibility aides or adapted vehicles - it should be noted that many schemes, such as the Housing Adaptations Grants, require expenditure in advance before reimbursement can be drawn-down retrospectively. This makes them completely inaccessible to a large section of disabled people who cannot accrue the capital needed for this type of expenditure and do not have equal credit options open to them via banks loans etc.

(5.2) The 'It Makes Sense' loans available to those in receipt of social welfare payments have a maximum of €2000 - which is insufficient to cover the costs of most housing adaptations, accessible vehicles and even many aides - such as wheelchairs or prosthetic limbs - and creates an unnecessary debt burden. These loans, even on the lowest interest rates, mean that the disabled person is taking on debt and losing part of their limited income unnecessarily; only the capital expenditure involved in such a loan is recoupable under current Grants, not the additional interest costs.

5. ii. Private market tenancy:

(5.3) A confluence of factors - including the fact that Part M of the Building Regulations not being fit for purpose as a measurement of a building's accessibility, particularly in private accommodation settings - has also had the effect of placing a price premium on features which are a convenience for others but which are absolutely essential accessibility requirements for a huge proportion of mobility-impaired people such as step-free ground-floor access and/or lift access. Disabled people may also have to pay a premium for essential accessibility features which are not recognised as such under the current Building Regulations, such as a low-sensory environment or a warm, damp-free home.

(5.4) Private tenants in Ireland have little to no right to make accessibility improvements to their homes. It is entirely at the discretion of the property owner to allow the installation of features such as grab bars in the bathroom, ramp installation, counter-top lowering, doorway widening etc.¹⁹

¹⁹ 'Housing Law, Rights & Policy', Dr. P. Kenna, Clarus Press, NUIG, (2011), Chapter 5: Particular Housing Needs, pp.280-334

These are noticeable and sometimes permanent changes to a property which very few landlords are willing to allow and, in the extremely rare cases where a private landlord grants permission, they are a significant, non-transferrable expenditure in someone else's property the cost of which is borne by the tenant.

“[For 4 years, I’ve been] living on campus which is extremely expensive, [the] college has four different [price] sections of accommodation... And it just so happens that the ones that are closest to the college are the most accessible ones and they’re also the most expensive ones... I’m a wheelchair user so I struggle to find accommodation that has no stairs, accessible bathrooms, all that kind of stuff. I had a housemate who was visually impaired and had a guide dog. It is illegal to turn her away because of her guide dog [but many] digs and student housing turned her away. So she also found herself living in the most accessible, expensive [student] housing. We talk a lot about how [the Disability Allowance] we receive per month is less than the rent we pay per month.”

(5.5) If someone in receipt of a disability-related social welfare payment also qualifies for HAP (Housing Assistance Payment), they may lose part of their disability allowance as ‘payment’ towards HAP, furthering financial hardship. Maintenance for rent or mortgage repayments is also subject to means testing limits and may reduce Disability Allowance received.²⁰

5. iii. Homelessness & precarious housing:

(5.6) The rate of disability among homeless people is 27%, double that of the general population (13.5%). Disability makes finding suitable accessible accommodation more difficult yet Housing Adaptation Grants and the Capital Assistance Scheme providing rental accommodation for those most at risk - including disabled people, older people and homeless people - have not yet returned to 2010 levels. Disabled people are more than twice as likely to report discrimination relating to housing and more than 1.6 times as likely to live in poor conditions such as living in damp housing or housing lacking central heating.²¹

6. Gendered impacts

(6.1) In its Concluding Observations published in August 2017, The Committee on the Rights of Persons with Disabilities raised concerns about the “lack of measures and available data concerning the impact of multiple and intersectional discrimination against women and girls with disabilities.” The Committee recommended that States, in line with the Committee’s General Comment No. 3 (2016) and targets 5.1, 5.2 and 5.5 of the Sustainable Development Goals, adopt inclusive and targeted measures, including disaggregated data, to prevent multiple and intersectional discrimination against disabled women and girls.²²

²⁰ The maintenance disregard for Disability Allowance is €95.23 as per Disability Allowance guidelines published by Irish National Organisation of the Unemployed:: <https://www.inou.ie/information/other-social-welfare-payments/disability-allowance/>

²¹ ‘Poverty and Social Exclusion of Persons with Disabilities’, European Human Rights Report Issue 4 - 2020, p.43: https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF_HR_Report_final_tagged_interactive_v2_accessible.pdf

²² ‘Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland’, Committee on the Rights of Persons with Disabilities: <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHkqMIT3RDALiqzhH8tVNxhro6S657eVNwuqlz u0xvsQUehREyYEQD%2BldQaLP31QDpRcmG35KYFtgGyAN%2BaB7cykvZ>

(6.2) DWI also wish to highlight the fact that many disability-related costs have a gendered and intersectional aspect. In consultations we conducted on specific Articles of the UN CRPD in March 2021, our members highlighted that the costs associated with disability can be higher for gender minorities due to their multiple intersecting identities. For example, costs associated with accommodation and transport can be higher for disabled women and other gender minority people who wish to avoid travelling long distances on foot, particularly late at night.

Gender minorities are also more likely to encounter financial barriers to healthcare, with 33% of disabled women in the EU reporting that they have been unable to afford needed healthcare.²³ All of this makes it incredibly difficult for disabled women to live independently and avoid becoming segregated or isolated from their communities. It also increases the risk of abuse at the hands of those close to them or in positions of influence at home, in the workplace or when socialising.

6. i. Employment and risk of poverty:

(6.3) With a labour force participation rate of 25.8%, disabled women are even less likely to be in paid employment than disabled men and are 25% more likely to live in poverty.²⁴ Disabled women's elevated risk of poverty and social exclusion rest on a number of interrelated factors involving both gender and disability.²⁵ Strategies to address the extremely high poverty and precariousness experienced by disabled women and other gender minority people require specific focus on this interaction; too often programmes aimed at increasing employment or reducing poverty amongst disabled people ignore gender, and gender equality policies tend to ignore the specific needs and experiences of disabled women. Both of these approaches leave disabled gender minority people behind.

The Dept. of Social Protection commissioned ERSI Report in June 2022 found: *"The most effective [way to reduce] AROP rates was increasing female labour force participation and hours worked to match those of men with similar characteristics."*²⁶

"As [disabled women] you get lower paid jobs anyway often, or you can only work part time. So the idea that you get a lower paid job to begin with, and ...the structures to progress in the system are so prohibitive that often even if you get in, you're not going to progress very far. You work part time. Your salary is very low. So the fact that then you actually lose [money and supports] is wrong."

(6.4) Gendered poverty is further complicated by gendered inequalities in employment itself: research from the UK²⁷ found that - adjusting for factors such as education, marital status, age,²⁸ employment status and family structure - the overall average pay gap for disabled women in the UK is 18.9%²⁹; 22.1% less than able-bodied men and still 11.8% less than disabled men.³⁰

Although we have yet to collect gender-disaggregated data in Ireland, it makes sense to believe that disabled women in Ireland experience a similar pay gap, as the overall gender pay gap in these countries is largely comparable. This highlights both the urgent need for specific gender-informed policies when it comes to disability-related employment strategies and for Government to collect gender-disaggregated data in all areas relating to disability.

²³ Gender Equality Index 2021, European Disability Forum: <https://www.edf-feph.org/gender-equality-index-2021-what-does-it-say-on-disability/>

²⁴ The Cost of Disability in Ireland Report., Indecon, p.37: <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>

²⁵ 'Women with Disabilities Are Still Struggling to Escape Poverty', National Women's Law Centre:

<https://nwl.org/blog/women-with-disabilities-still-struggling-to-escape-poverty/>

²⁶ Dept. of Social Protection Research Briefing 'Headline Poverty Target Reduction in Ireland and the Role of Work and Social Welfare', ESRI (June 2022), p.20

²⁷ 'Life Opportunities Survey: wave 3 results', UK's National Statistics Office (England, Scotland & Wales) (2015):

<http://www.ons.gov.uk/ons/rel/life-opportunities-survey/wave-three-final-report-october-2012-to-september-2014/index.html>

²⁸ 'Disabled Women and Austerity', Briefing from the UK Women's Budget Group (2018):

<https://wbg.org.uk/wp-content/uploads/2018/10/Disabled-women-October-2018-w-cover-2.pdf>

²⁹ The 'double whammy' of being a disabled woman in the UK', Caroline Waters, Equality & Human Rights Commission (2018):

<https://www.equalityhumanrights.com/en/our-work/blogs/%E2%80%98double-whammy%E2%80%99-being-disabled-woman-uk>

³⁰ Source: 'Disabled Women and Austerity', Key Findings from the Briefing from the UK Women's Budget Group (2018), p.2

6. ii. Gender discrepancies in access to State support:

(6.5) Women are more likely to be disabled than men,³¹ and disabled women are less likely to be in paid employment than men,³² however women are less likely than men to receive Disability Allowance in Ireland.³³ Although DWI do not have access to the information needed to account for this discrepancy, outside anecdotal accounts, we are concerned that it indicates that some disabled women are falling through the social safety net and believe that it requires investigation. Some of this discrepancy will be tied to means testing of disability supports against partner's income, but lived experiences amongst our membership indicate that aspects of financial coercion may also be at play.

(6.6) Approximately 60% of disabled people in Europe are women or girls,^{34 35} but women and girls account for only 51.6% of disabled people in Irish statistics.³⁶ Based on consultations with our members, we believe this discrepancy highlights systemic issues with gender equity in access to diagnosis and support in Ireland.

Our members have reported encountering widespread dismissal, disbelief, misdiagnosis and lack of knowledge regarding gendered presentations of many conditions across the Irish healthcare system as well as significant financial barriers in accessing appropriate diagnostic services. This is exacerbated by the lack of publicly available adult diagnostic services across a range of conditions - many of which are particularly needed by women and other gender minorities - as this creates a huge financial barrier to those whose only option is private diagnosis (for example, for autism), or to travel to countries where diagnosis is available (for example, for Ehlers-Danlos Syndrome).

“Due to lack of public pathways and enormous waitlists I had to, as a disabled parent to a disabled child, try to figure out which of us to prioritise for diagnosis that would be most beneficial for our family. We could not afford both and needed to borrow a substantial amount of money to find support for our child. This means I have no access to disability payments or supports that I need”.

(6.7) Gender inequities in diagnosis are further compounded by outdated classifications of disability which replicate gendered assumptions of the time they were written, particularly for conditions which are significantly more common amongst women and other gender minority people. To give just one example, it has been more than a decade since the European Parliament adopted a declaration calling for the recognition of Fibromyalgia - a painful and debilitating condition which is 9 times more common in women³⁷ - as a disability in all EU States³⁸ yet it has still not been granted official recognition in Ireland.³⁹ A review process for conditions and impairments recognised under Irish legislation needs to be established to ensure that such oversights can be prevented in future and that individuals are not excluded from social supports, particularly as we don't yet know the full extent of the ways in which post-viral syndromes in those infected with Covid 19 will express across the population.⁴⁰

³¹ Source: EuroStat analysis of the European health and social integration survey (EHSIS) 2012 and the EU Labour Force Survey (LFS) 2011.

³² Source: Indecon Cost of Disability report 2021, CSO Census Data 2016.

³³ 'Spending Review 2017 Disability Allowance Expenditure Drivers', Niamh Callaghan, Employment Affairs and Social Protection, Vote Department of Public Expenditure and Reform (2017): <https://assets.gov.ie/7268/483351e0c87ef4600a615494e152f1ba8.pdf>

³⁴ 'Women and girls with a disability – Active Inclusion and Equal Opportunities', European Platform for Rehabilitation (December 2019), p.4: <https://epr.eu/wp-content/uploads/Analytical-Paper-on-Women-with-Disabilities-2.pdf>

³⁵ Source: EuroStat analysis of the European health and social integration survey (EHSIS) 2012 and the EU Labour Force Survey (LFS) 2011

³⁶ Census of Population 2016, Profile 9 Health, Disability & Carers', CSO: <https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9d/>

³⁷ 'The role of gender in fibromyalgia syndrome', M.B. Yunus, Current Rheumatology Reports, (2001): <https://pubmed.ncbi.nlm.nih.gov/11286669/>

³⁸ Written Declaration 69/2008 on Fibromyalgia, adopted by the European Parliament on 13 January 2009

³⁹ Blessing Dada (2019): <https://www.change.org/p/fibromyalgia-me-cfs-to-be-declared-as-an-official-disability?s=08>

⁴⁰ 'Long COVID and Post-infective Fatigue Syndrome: A Review', C.X. Sandler et al. Open Forum Infect Dis. (Oct. 2021); 8(10): [doi: 10.1093/ofid/ofab440](https://doi.org/10.1093/ofid/ofab440)

6. iii. Financial dependence and increased risk of gender-based violence

“Poverty and inequality contribute, as stressors, to acts of abuse and also at extremes can be considered as a kind of violence”

Council of Europe Violence against Vulnerable Groups Project⁴¹

Lack of financial independence has been found to be one of the most significant risk factors in being exposed to intimate partner violence.⁴² Financial dependence is also the most common barrier to escaping an abusive relationship.⁴³

(6.8) According to an Irish report, disabled women are, on average, 3 times more likely to be subjected to intimate violence as non-disabled women⁴⁴ (international research more usually puts this increased risk at 4-5 times).⁴⁵ The reasons for this encompass societal attitudes and perceptions of vulnerability but a core foundation, highlighted by our members in consultations and backed up by international research, is disabled women’s lack of financial independence.⁴⁶ Vulnerability isn’t an aspect of a disabled person’s body in isolation, rather it is the disempowering structures and systems within which we live which cause us to be vulnerable.

“Working as a refuge worker in a Domestic Violence service, I am aware of disabled women who have only been able to access phone support and have no hope of leaving their abusive relationship because their welfare payments are tied to the income of their abuser”

(6.9) Financial dependence is a major risk factor in both experiencing gender-based violence and in being unable to successfully seek support to escape from it.⁴⁷ Means testing of disability payments and supports creates an enormous dependence for a disabled person on their partner, and an associated vulnerability to partner abuse including elevated rates of financial abuse.⁴⁸ Frequently, access to money, food, medication and/or assistive equipment such as mobility aids is restricted in disabled people’s experience of abuse in addition to the forms of violence experienced by non-disabled people.⁴⁹ Lack of portability of disability supports and State reliance on family members as *de facto* caregivers to disabled people compound the already increased difficulty of leaving an abusive relationship caused by lack of money and almost-universal inaccessibility of gender-based violence support services.⁴⁸

(6.10) The fact that a disabled person’s disability-related allowances and supports are not tied to their disability but rather to the circumstances of the people around them - and that their right to personal assistance is generally conditional on their not having a family member able to act as their caregiver - increases their vulnerability to all types of exploitation and abuse and contributes to the widespread negative societal perception that they are a ‘burden’ on their family. This systemic over-reliance on the ‘goodwill’ of family members is a significant contributory factor to disabled people’s high rates of

⁴¹ Violence against vulnerable groups Integrated project, Council of Europe Publishing: ‘Responses to violence in everyday life in a democratic society’, H. Brown, (2004) p.38. ISBN 978-92-871-5447-7

⁴² ‘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/>

⁴³ ‘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)

⁴⁴ ‘Domestic Violence and abuse against people with disabilities’, NDA paper to the Committee on Justice, Defence & Equality (2013):

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

⁴⁵ ‘Physical and sexual assault of women with disabilities.’, S. Martin et al. (2006). Violence against women. 12. 823-37. <https://pubmed.ncbi.nlm.nih.gov/16905675/>

⁴⁶ ‘Is economic dependence on the husband a risk factor for intimate partner violence against female factory workers in Nepal?’, S. Dhungel et al (2017): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5598058/>

⁴⁷ ‘Women, disability and violence: Barriers to accessing justice’, Australia’s National Research Org. for Women’s Safety Maher et al., Horizons, (2018). <https://20ian81kyngq38b3l3eh8bf-wpengine.netdna-ssl.com/wp-content/uploads/2019/02/Maher-et-al-Horizons-Research-Report.pdf>

⁴⁸ Women, disability and violence: Barriers to accessing justice: Final Report’, Maher et al. Horizons Issue 2 (2018).

⁴⁹ Disabled Women & Austerity: <https://wbq.org.uk/wp-content/uploads/2018/10/Disabled-women-October-2018-w-cover-2.pdf>

social inclusion, as the State is not upholding the disabled person's right to full inclusion in their communities based on their own will and preferences. Statutory provision of home help services can reduce social isolation experienced by family caregivers, but does not tackle social exclusion experienced by disabled people or advance other their rights under the CRPD as a Home Help only performs pre-determined tasks in the home; a transition to a national statutory Personal Assistance Service framework is urgently needed.

“Say you want to get married, you're giving up a lot more independence and autonomy because you're on Disability Allowance. You're really kind of putting all your eggs in one basket and kind of very vulnerable if something goes wrong.”

Conclusions and Priority Recommendations:

- **Expand Cost of Disability Payment introduced in Budget 2023 without upper age limit.**
- **Expand access to Personal Assistance Services on a statutory basis nationally.**
- **Complete transition to needs-based access to supports and services as a priority.**

We strongly urge the Government to raise national ambition and work towards bringing targets for consistent poverty reduction for disabled people in line with, as the Roadmap itself puts it elsewhere, the “norm for other people in society”⁵⁰ in order to uphold the State's commitment to equality for disabled people in all aspects of life. Someone who cannot afford to travel to their nearest town nor to attend social events will remain excluded from day-to-day life. Their opportunities for paid employment will also be restricted. We also ask you to raise ambition in reforming the structure of disability related supports; to move away from a complex and problematic means-tested framework in order to mitigate the additional gendered risks and attendant structural vulnerability we have outlined in this submission. To state it plainly; a disabled woman trapped in an abusive relationship by financial dependence, due to her partner's income reducing or removing her disability supports, will be no safer and in no better a position to regain control of her life by an increase in payments if it isn't accompanied by removal of the means-testing requirement as a whole.

The conditional and transactional framework from which means testing arose is an impediment to transitioning from a charitable or medical model of disability towards the rights-based social model that Ireland has committed to under the UN CRPD. Furthermore, means-testing negatively colours the way disability is perceived in wider society. Framing our right to access the support we need to participate in society on an equal basis with others as dependent on the means of our family members perpetuates the idea that we are a burden. It codifies a system whereby only those of us without family support, or those of us whose families are unable to bear the cost of this 'burden', deserve assistance and support to offset the cost of our disability in a largely inaccessible society.

We therefore strongly urge the Mid-Term Review to explore expansion of the Cost of Disability payment introduced in the recent Budget over incremental increases to current means tested supports, implementation of the recommendations of the Joint Oireachtas Committee's Disability Matters report *'Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities'*,⁵¹ - most urgently the expansion of the successful Personal Assistance Services pilot scheme on a national statutory basis - and transitioning to a needs-based rather than diagnosis-based framework for the allocation of access to services and supports as the only realistic roadmap to meaningful social inclusion for disabled people in Ireland.

⁵⁰ 'Roadmap for Social Inclusion 2020 - 2025', Department of Social Protection, Chapter 6: Supporting People with Disabilities, p.55.

⁵¹ 'Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities', Joint Oireachtas Committee's Disability Matters: https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/reports/2022/2022-03-10_report-on-ensuring-independent-living-and-the-united-nations-convention-on-the-rights-of-persons-with-disabilities_en.pdf

Detailed List of Recommendations and Roadmap Goals impacted:

To ensure an autonomous and adequate standard of living and social protection for disabled people:

1. Remove means testing from disability-related payments and supports to address disabled people's lack of independence and control over their own lives, and to show State commitment to CRPD principles of equality of opportunity in all aspects of life. **(Goals 1, 4⁵² & 5)**
2. Reframe qualifying criteria for disability payments and supports to being based on support need, rather than age-based criteria assessing impediment to paid employment. This will go some way towards addressing barriers to employment and higher rates of poverty in employment experienced by disabled people, as well as providing a solid foundation to tackle the significant rates of poverty amongst older disabled people. **(Goals 1, 3, 5 & 7)**
3. Benchmark disability-related payments against median incomes to ensure that they remain above the poverty line as determined by the CSO. **(Goals 3, 4, 5 & 7)**
4. Adjust specific financial support schemes, such as the Housing Adaptation Grants, to be delivered as an up-front grant for successful applications to ensure they can be accessed by all who need them. Explore options for incorporating weighting for environmentally-friendly design and quality in the grant assessment process for quotes tendered to the applicant, alongside pricing. **(Goals 3 & 5)**
5. Prioritise reintroduction or replacement of the suspended Motorised Transport Grant and the Mobility Allowance scheme to offset the widespread inaccessibility of public transportation and rising costs of private transportation which sees many disabled people isolated in their homes and unable to fully participate in community life, particularly in rural areas. **(Goals 1, 3, 5 & 7)**
6. Review the Disabled Drivers & Passengers Scheme to ensure it meets current purchasing costs for accessible vehicles and to future-proof it against 'phasing out' of diesel / petrol vehicles. **(as above)**
7. Fully implement the recommendations of the Make Work Pay report and remove the financial and practical barriers to employment outlined in this submission. **(Goals 1 & 2)**
8. Urgently review and rectify discrepancies between the Disability Allowance, the Blind Pension and other supports to prevent systemic discrimination the basis of impairment type. **(Goals 1 & 5)**
9. Ensure that disability-related therapies, rehabilitative programmes and support are granted on the basis of need, not on Medical Card status or means testing. **(Goals 5 & 7)**
10. Move towards a model of delivering disability supports as personalised budgets which are based on each individual's need and are not tied to their family circumstances to ensure that disabled people are empowered to exercise their will and preferences in line with the CRPD. **(Goals 1 & 5)**
11. Develop specific policies to target poverty and social exclusion amongst gender and ethnic minorities, informed by DPOs and other expert stakeholders, and develop measures to address the 'gender-and-disability' pay gap experienced by those in paid employment. **(Goals 1, 2 & 5)**
12. Develop specific policies enabling the collection of gender-disaggregated data in relation to the financial situation and experiences of social exclusion of disabled gender minorities. **(as above)**
13. Adopt disability-adjusted standard poverty measurements to capture the differences in standards of living between disabled people and non-disabled people on similar incomes, and to meaningfully inform national strategies aimed at reducing poverty and social exclusion. **(Goals 1, 3 & 5)**
14. Create an urgent focus on the shocking levels of violence disabled gender minority people are subjected to. As with all other people, disabled people cannot achieve economic parity and an adequate standard of living until they are free from the spectre of frequent violence. **(Goal 5)**
15. Implement Sláintecare and the resourcing of community healthcare centres as soon as possible. Review diagnostic and medical services to eradicate gender biases and shortfalls. **(Goal 7)**

⁵² Children who live in families with one or more disabled parent(s) experience the highest rates of income poverty (AROP), deprivation and consistent poverty. Source: Dept. of Social Protection Research Briefing 'Headline Poverty Target Reduction in Ireland and the Role of Work and Social Welfare', ESRI (June 2022).