

# DÁIL ÉIREANN

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## AN COMHCHOISTE UM AIRGEADAS, CAITEACHAS POIBLÍ AGUS ATHCHÓIRIÚ, AGUS AN TAOISEACH

### JOINT COMMITTEE ON FINANCE, PUBLIC EXPENDITURE AND REFORM, AND TAOISEACH

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*Déardaoin, 10 Márta 2022*

*Thursday, 10 March 2022*

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Tháinig an Comhchoiste le chéile ag 9.30 a.m.

The Joint Committee met at 9.30 a.m.

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Comhaltaí a bhí i láthair/Members present:

Teachtaí Dála/Deputies	Seanadóirí/Senators
Bernard J. Durkan,	Aidan Davitt,
Mairéad Farrell,	Alice-Mary Higgins.
Jim O'Callaghan.	

I láthair/In attendance: Deputies Holly Cairns, Seán Canney, Michael Moynihan, Jennifer Murnane O'Connor and Pauline Tully and Senators Erin McGreehan, Fiona O'Loughlin and Mary Seery Kearney.

Teachta/Deputy Mairéad Farrell sa Chathaoir/in the Chair.

*Deputies Michael Moynihan, Mairéad Farrell and Jim O'Callaghan co-chaired the joint meeting.*

## **Joint Meeting with Joint Committee on Disability Matters**

### **Enabling Financial Independence for Women with Disabilities: Discussion**

**Co-Chairman (Deputy Michael Moynihan):** In accordance with the current guidelines, all documentation for the meeting has been circulated to members using the Microsoft Teams platform.

This morning's meeting is a joint meeting of the Joint Committee on Disability Matters and the Joint Committee on Finance, Public Expenditure and Reform, and Taoiseach. Everyone is welcome. The purpose of the meeting is to discuss enabling financial independence for women with disabilities. I extend a warm welcome and a céad míle fáilte to the Ms Nicola Meacle and Ms Paula Soraghan from Independent Living Movement Ireland and, from Disabled Women Ireland, Ms Amy Hassett, Nem Kearns and Ms Aoife Price.

Before we begin, I must take us through a few housekeeping matters. Witnesses are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against any person or entity by name or in such a way as to make him, her or it identifiable or otherwise engage in speech that might be regarded as damaging the good name of a person or entity. Therefore, if their statements are potentially defamatory in respect of identifying a person, they will be directed to discontinue their remarks. It is imperative they comply with such direction. For witnesses attending remotely outside of Leinster House, there are some limitations to parliamentary privilege and, as such, they may not benefit from the same level of immunity from legal proceedings as witnesses presenting physically or within the confines of Leinster House.

Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against any person outside of the House. For anybody watching the proceedings of our meetings, Oireachtas Members and witnesses now have the option of being physically present in the committee room or joining the meeting remotely by Microsoft Teams. I remind members of the constitutional requirements that members must be physically present within the confines of Leinster House.

I call Ms Nicola Meacle to make her opening statement.

**Ms Nicola Meacle:** I thank the Cathaoirleach and members of the committee for the invitation to contribute today. I am delighted to be here and to be joined by my colleague, Ms Paula Soraghan. As a disabled woman who works with the Independent Living Movement Ireland, ILMI, I want to speak about, namely, a brief introduction to the philosophy of independent living as it pertains to full participation in society and equal citizenship, how financial independence for disabled women would facilitate them to participate fully in their community and how poverty diminishes the quality of disabled women's lives and prevents them from achieving their potential.

To give a brief introduction to the ILMI, it is a campaigning, national representative cross-

impairment disabled persons organisation, DPO. No discussion of financial independence for disabled women can occur without acknowledging independent living and the social model of disability. Independent living refers to the freedom to have the same choices everyone else has in housing, education and employment and to fully participate in an inclusive society. The social model of disability recognises the structural and attitudinal barriers that limit disabled woman from achieving their potential and creates the conditions that impoverish them. Enabling financial independence for disabled women means addressing the root causes of inequality and acknowledging the role gender plays in exacerbating that injustice.

There has been extensive national and international research that confirms disabled people incur extra financial costs such as extra heating, dietary requirements, prescription fees, taxi fares, not to mention paying privately to supplement inadequate personal assistant, PA, support if in a position to do so. In 2021, the Department of Social Protection commissioned Indecon International Research Economists to research the cost of disability; however, it was commissioned earlier and published in 2021. The findings confirmed there are significant additional costs faced by individuals with a disability that are currently not met by existing programmes or social welfare payments. The analysis shows the actual costs faced by individuals with severe disabilities, on average, range from €9,600 to €12,300 per annum and for those with limited disabilities from €8,700 to €10,000 per annum. In addition to the additional costs incurred by individuals with a disability, there are unmet costs faced by many as they are not currently affordable. Individuals with a disability face enormous challenges to live independently and face a high risk of poverty and social exclusion. The report points out that income supports alone will not resolve the financial inequality. It requires a broader perspective covering areas such as employment, housing, transport, education and health. This is in alignment with the philosophy of independent living, which recognises the need for an holistic approach that underpins policies for access to housing, transport, employment and living independently.

On 20 March 2018, the Government ratified the UN Convention on the Rights of Persons with Disabilities, UNCRPD. In December 2020, the State submitted its initial progress report under the various headings included in the convention. Article 6 of the convention refers specifically to women. The State has observed in its report “that disabled women and young girls experience discrimination and that the State will work to make sure that disabled women and young girls have the same human rights and freedoms as others”. For many disabled women being a woman with a disability is like having a double disability such is the level of discrimination experienced. The report also recognises that women and girls with a disability face multiple barriers to the realisation of their rights. Nevertheless, the lack of an explicit reference to a cost-of-disability payment in the report and the link between poverty and social exclusion does not indicate that financial independence is seen as a priority.

Article 27 refers to disabled people and employment. The barriers disabled women experience result in lower labour force participation, with a participation rate of 26% among disabled women in 2016 compared to 35% for disabled men. One reason disabled women are caught in a poverty trap is a fear that taking up employment could cause the loss of a medical card and other social welfare payments. I am aware there are supports and programmes to encourage disabled women to enter the labour market without the loss of certain benefits but the fear of any threat to the medical card is real. Even if somebody with an impairment enjoys good health, the medical card entitles those with one to expensive equipment such as a wheelchair. It highlights how the financial implications of risking loss of the medical card prevents people joining the labour market. Unemployment also leads to social isolation and an inability to participate in the economic and social life of their community.

Even when disabled people work, there is the cost of travelling to and from work. In 2013, the State abolished the motorised transport grant, which contributed towards the purchase a car if needed to get to work. The fact that social welfare payments are means tested and the income of a spouse, cohabitant or civil partner is taken into consideration can mean a person does not qualify for a payment in his or her own right. The impact of this is that when a disabled woman does not have an adequate PA service to live independently and cannot afford to supplement her PA service, she can be prevented from leaving an abusive relationship if she is dependent on that person for her support needs.

Access to education clearly correlates with future earning power, if disabled women are to achieve financial independence, then equal access to education is essential. Getting to college requires supports such as transport and for some disabled women, personal assistance.

To sum up, I reiterate that to make the choices and options inherent in the philosophy of independent living a reality and to establish financial independence for disabled women, a cost-of-disability payment that compensates for the extra financial costs of living as a disabled person needs to be prioritised. The Indecon report cannot be allowed to be ignored or forgotten about. I thank all members of the joint committee who are here this morning for listening to me and for giving me this opportunity.

**Co-Chairman (Deputy Michael Moynihan):** I thank Ms Meacle. I call Nem Kearns to make some opening remarks.

**Nem Kearns:** We would like to thank members of both committees here today for inviting us to speak with them regarding the financial barriers disabled women experience and how these can be removed. To tackle the poverty and social exclusion shadowing disabled women's lives, we first need to understand the multiple and intersecting forms of discrimination they face and create targeted measures to dismantle these barriers. While we will use the word "women" throughout our statement this is only because the little data available for disabled women does not exist for other gender minorities. We have no reason to believe they encounter fewer barriers than disabled women do. In fact, inequalities highlighted here are exacerbated for disabled people belonging to other marginalised communities such as the ethnic minority or LGBTQ communities and those in institutional settings such as direct provision or the penal system.

Disabled women in Ireland experience deprivation and social exclusion at an even greater rate than disabled men. They are 25% more likely to live in poverty and only one quarter of disabled women are in paid employment of any kind. Up to one third of all women experiencing homelessness in Ireland are disabled and the list goes on.

Gendered inequalities impact almost every aspect of life. Creating a country truly committed to realising the UNCRPD requires an ambitious reimagining of State support, moving away from an adversarial, medicalised system to a rights-based approach providing equal opportunity to both pursue a full and meaningful life. To this end, we wish to reiterate how crucial it is that all demographic data collected by the State is fully disaggregated and to briefly highlight just three of the many ways in which the current one-size-fits-all system fails to account for the interactions between gender, disability and poverty. Means testing imposes unnecessary restrictions on employment, contributing to Ireland having the highest unemployment rate for disabled people. The National Strategy for Women and Girls 2017-2020 notes disabled women's greater marginalisation and states this should be addressed through the National Disability Inclusion Strategy 2017-2021, NDIS. The NDIS action plan, however, contains only one mention of women, and the Comprehensive Employment Strategy for People with Disabilities does

not mention women at all.

While gender receives some attention in implementation, tackling gender inequality needs to be prioritised at the highest strategic level to ensure a whole-of-government approach. Some 67% of disabled women are parents and 45% of family carers in Ireland are disabled. Due, in part, to these extra responsibilities, disabled women are more likely to work in the more flexible industries such as the arts sector or in part-time work in the caring professions. Many live in fear that unexpected circumstances may put them over the means test thresholds and in danger of losing all support while others are too afraid to pursue employment at all. Given that disabled women outnumber disabled men and are almost one sixth less likely to be in paid work, we would expect to find more women than men relying on supports such as the disability allowance. Disabled women, however, are actually less likely to receive disability allowance in Ireland.

Treating disability payments as a kind of jobseeker's allowance for disabled people fails to tackle the root causes of systemic poverty. We need a new approach. Disability supports can be a powerful tool to reduce inequality but only when recognised as a means to offset the significant cost of disability and to break cycles of poverty and exclusion instead of as a replacement for income. A diagnosis-driven assessment disadvantages women, who encounter more healthcare barriers. Ireland's disability gender ratio is well below the EU average, indicating many women struggle to secure a diagnosis. Our members reported frequent dismissal, disbelief, misdiagnosis and widespread lack of knowledge regarding gender differences in many conditions as well as significant financial barriers to diagnosis.

Gender bias exists in medical practice and at State level. More autistic women than men remain undiagnosed into adulthood, but Ireland has no public pathways for adult diagnosis. Fibromyalgia, which is nine times more common in women, lacks official recognition in Ireland more than ten years after an EU declaration to address this. For women, receiving diagnosis for some conditions such as Ehlers-Danlos syndrome, EDS, takes an average of 12 extra years, resulting in a significant extra cost to travel abroad as it cannot be diagnosed in Ireland. Too many fall through the cracks of our current assessment system, as shown by the nearly two thirds of disability allowance applications that were denied and overturned on appeal. A universal needs-led payment would go a long way to counterbalancing these inequalities while also relieving the State of significant administrative costs through streamlining the assessment process.

As well as undermining disabled women's financial security, means testing can also force them into positions of dependency. Lack of financial independence is one of the most significant risk factors in experiencing gender-based violence, and financial dependency is also the most common barrier to escaping an abusive relationship. Violence increases a survivor's risk of poverty and undermines their long-term health. Disabled women in Ireland are three times as likely to be subjected to domestic violence than non-disabled women and up to five times more likely to experience all types of gender-based violence.

Making disability-related supports provisional on the income of other people places disabled people in a very dependent position and at a much higher risk of violence and abuse. Lack of portability of disability supports and State reliance on family members as de facto caregivers compounds this dependency. Without access to personal assistance, disabled women needing support have little control over who comes into their home.

Disabled Women Ireland, DWI, has also heard many accounts of women threatened with or

experiencing having their children taken from them should they leave their abuser. This fear is real and common. An Australian study found that most disabled women who reported domestic violence had their children removed from their care by the state.

This year Ireland, once again, has begun having a national conversation about gender-based violence and the toll it takes on our lives. Once again, the voices of disabled women are missing. More than 80% of us are subjected to gender-based violence in our lifetimes. We can no longer wait for the conversation to come around to us. We need to talk about why, as a country, we have silently abandoned some of our siblings to live in poverty and the shadow of violence. Too many assume the scale of abuse disabled women endure is because we are inherently more vulnerable and that disability somehow births this violence. Too few recognise that vulnerability is created by a society pushing people to its margins. Vulnerability is not an individual characteristic; it is measured in the spaces between power, security and marginalisation. We must shine a light on all of the ways in which, as disabled people, our control over our lives, independence and even our bodies has been undermined by the systems we have inherited and make the radical changes needed to break these cycles of disempowerment.

No disabled person should be made to feel their independence is so fragile, so conditional and so easily taken away that they need to live in fear, whether of the State, of the service provider, or of someone in their own home. I thank the committee for its time.

**Co-Chairman (Deputy Michael Moynihan):** Thank you for your contribution. The format for questions and answers is that we will commence with questions from the Joint Committee on Disability Matters and then from the Joint Committee on Finance, Public Expenditure and Reform, and Taoiseach, with members from the respective committees being called in groups of two.

**Senator Mary Seery Kearney:** I thank the Co-Chairman and our contributors. On International Women's Day, I have to say that many of the faces are familiar to me because I have heard powerfully from these speakers before. They are not storytellers. I want them to be powerful influencers, as they are to me. This day last year when we heard similar statements, it transformed how I thought about everything throughout the year. We cannot keep coming back, however, and have the same issues raised every year without seeing change. We now have a report on the cost of disability, so what are we doing with it? That needs to be a very powerful message coming out of this meeting, and I will raise this exact point in the Seanad.

It is shocking we have the lowest rate of employment of people with disabilities in the EU and that women are more disproportionately affected by that. Yet, on the other hand, it is not surprising because that is discrimination against women, full stop, and of course there will be that additional discrimination against women with disabilities.

It would be remiss of me not to raise the issue of the mobility allowance because we had Maureen on a call to the committee last week, who is from my own constituency of Dublin South-Central and is a powerful advocate for the reinstatement of the mobility allowance and the freedom that comes from that. I would welcome our guest speakers' comments on that.

Given the figures that were put in front of us, the €208 a week allowance versus the weekly minimum wage of €366 and then the additional cost of disability of €226 a week, there certainly needs to be a clear focus on ensuring people with disabilities have an adequate allowance and on removing the means testing.



I welcome all of our guests' comments on gender-based violence. It is a particular passion of mine to talk about and advance this issue, and in doing that I consistently come back to how the level of dependence absolutely disempowers women with disabilities. For a person even to consider making the call for assistance entails an additional row of impediments to have to cross before even beginning to think about their own safety, let alone that of their children. We need to have a very specific conversation on that, on women with disabilities, and on how we are supporting them in that regard.

On the criteria for the primary medical health certificate and the fact that even amputees cannot qualify for it, it is outrageous we are still having that conversation, and we very much need to move it on.

I know our guests are presenting to us here today on very existential issues of the sheer ordinary cost of living and the difficulties in that. Part of my own priorities and agenda is fertility treatment and access to it. You cannot look at the figures and the constraints on women with disabilities and not conclude that access to fertility treatments is probably out of any realm. It is expensive for a couple in really good jobs to access because it is in the private arena and we do not have any public funding for it. I would value the witnesses' comments on that. It is, I have no doubt, part of a somewhat paternalistic assumption, bias and stereotyping of not prioritising women with disabilities for fertility treatment when they probably should be prioritised.

**Deputy Pauline Tully:** I thank the witnesses for their very informative and detailed presentations on many of the issues that are a cause for concern. Both organisations are disabled people's organisations, DPOs, one of which specifically represents women while the other represents men and women. I am interested in hearing the witnesses' experiences of consultation with various groups. One of the cornerstones of the UN Convention on the Rights of Persons with Disabilities, UNCRPD, is consultation with DPOs and disabled people. Were the organisations consulted, for example, on the Indecon review on the cost of disability, which was carried out and published last year? We are told its findings are being considered and, it is hoped, addressed. Were the organisations consulted and, if so, what were their recommendations? If not, I would like to hear what recommendations they would have made. I believe both organisations should have been consulted.

It was mentioned that the national disability inclusion strategy references women only once and that the comprehensive employment strategy for people with disabilities does not reference women at all. That is concerning, especially as the employment rate for disabled women is considered to be lower than it is for men. It is low in general for disabled people, but it is even lower for disabled women. Why is there such a discrepancy there?

There has been a great deal of focus in recent times on domestic and gender-based violence. We know one in four women will endure or experience violence. The witnesses have stated the ratio in that regard for women with disabilities is higher and that, because the disability payment is mean tested, women with a disability who are in a partnership or marriage become reliant on their partner and that makes it harder to leave. Have the witnesses been consulted in regard to the third national strategy on domestic, sexual and gender-based violence? I would appreciate it if the witnesses could address those points.

**Co-Chairman (Deputy Michael Moynihan):** I now invite the witnesses to address the questions from Senator Seery Kearney and Deputy Tully, starting with Ms Hassett.

**Ms Amy Hassett:** I will try to do a whistle-stop tour. I am sure the other witnesses can help

me out with that. I will make one very specific point in regard to fertility treatment. The legislation that is currently proposed on fertility treatment explicitly allows mostly private clinics to discriminate based on disability. Cost is a major concern for us, but there is also an element of discrimination. Under Article 23 of the UNCRPD, disabled people have a right to have a family and to be supported in having a family.

We would support the reinstatement of the mobility allowance. Access to transport, the ability to get around, is a cornerstone issue that can help to improve many of the other problems. In terms of cost of disability and the cost of living, we know the cost of living is ever-increasing and that disabled people are particularly affected by that. We have called for the cessation of the means testing of the disability allowance payment and for the disability allowance to become a cost of disability payment. There is a precedent for this within Irish legislation in terms of the domiciliary care allowance, which, although wholly inadequate, is a payment given to carers of young disabled people that is not means tested. It is specifically to cover the cost of disability. For some reason, once a person with a disability turns 16, it is expected that the cost of disability will be absorbed within payments relating to general cost of living, which makes no sense.

On consultation, the consultation processes in recent months have not been entirely inclusive of disabled people and disabled persons' organisations. There are a couple of specific examples. Some of the members present were part of the recent discussion process around the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 and the codes of practice for the disability support service, which is part of the ADM. In both instances, the consultation process was not accessible. Materials were not provided in accessible format, the timeframe was incredibly short and we were not supported to be part of these processes. This is something we are seeing across the board. We would have significant concerns around that.

**Nem Kearns:** I would like to expand, with a little more specific detail, on Ms Hassett's response to Deputy Tully's questions. On the Indecon report, we were not directly consulted. We did promote it to our membership to encourage as much involvement as possible but we were not directly approached. In regard to the third national strategy on domestic, sexual and gender-based violence, we were involved in the consultation but only because we actively pursued it. Disabled Women Ireland, as the only gender-based DPO in the country, was not approached. We are experiencing that a lot. We are receiving more requests for consultation, but there are a lot of concerns around the consultation process, including that there is no commitment to what that means. We have taken part in very time-consuming consultation with various branches of government and semi-State bodies and had none of our recommendations or feedback taken on board, with no explanation in that regard. The consultation process must be robust such that we can see what is happening.

We have received no support for consultation, as required under the UNCRPD. Disabled Women Ireland is entirely run by disabled volunteers and on an unfunded basis. That will limit our ability to engage in the required level of consultation for implementation of the UNCRPD, especially as the means testing affects disabled people very directly. If we do secure funding, we will not be able to pay our members for the amazing number of hours and amount of work they put in because it might cost them their disability support. This is an issue that will directly impact the implementation of the UNCRPD in Ireland.

On the right to a family and assisted human reproduction, alarms have been sounded that disabled people are not fully included. Disabled women in this country continue to be put on long-term contraception against their will and without their consent. There is still a huge gap between guidelines in legislation and actual practice. There are guidelines stating that dis-



crimination against disabled people in regard to fostering, adopting and many other areas is not permissible. However, in practice that is happening on the ground. Most of the people working on the ground seem completely unaware that discrimination is not upheld by law. They think it is a valid reason. We are very concerned about these areas.

**Ms Nicola Meacle:** I will be brief. I want to respond to Senator Seery Kearney's comments on transport. Transport is one of the four pillars of independent living. The four pillars are housing, personal assistance, transport and the accessible environment. If someone cannot get to work, that is an issue. There are supports such as the VAT rebate and the initial cost of a vehicle but it is still enormously expensive if it is your first job. I would like to see a programme such as those run in the UK like Motability where you can lease a vehicle. You do not own it but you have the benefit and use of it in an affordable way.

It has become much more difficult to get a primary medical certificate to get the concessions to purchase a vehicle. There were abuses in the past but it has gone to the other extreme now. It needs to be more nuanced.

On consultation and the cost of disability review, information was sent out ILMI members but the organisation itself was not directly consulted.

**Ms Aoife Price:** I want to pick up on an important point made in the submission on means testing and the financial vulnerability of disabled women. It leads to disabled women not being active in the community and that leads to isolation. That leads to greater vulnerability when they may face gender-based violence. We are really isolating disabled women from society and making them more vulnerable and more at risk in many areas.

**Ms Paula Soraghan:** I want to reiterate some of the points made by Disabled Women Ireland and Ms Meacle. As a disabled woman, it all comes back to choice. We need to ensure that disabled people and women have the choices in their lives to be able to make decisions that directly affect them. So many barriers are in place and disabled women do not have as many choices available around how we live our lives independently. I appreciate that everyone's circumstances are different. However it is a shame that the disability allowance is means tested. I do not have a disability allowance because I am privileged to work in a full-time position but the means test does much more harm than good. I echo the points made by Disabled Women Ireland. There must be more engagement with disabled persons organisations. Independent Living Movement Ireland really appreciates the opportunity to be here today to speak on this with Disabled Women Ireland.

I echo Nem Kearns's point on consultations. It is one thing to have those consultations but often disabled organisations must really fight to be there in the room. It is great that consultations have taken place but implementation is another issue. We need more implementation around the issues we are discussing today. We value the opportunity of being here to highlight the very serious issue that we all face.

**Deputy Bernard J. Durkan:** I have listened with interest to the points raised and agree that we must level the playing pitches insofar as it can be done for everybody. The purpose of the exercise is to make everyone's life easier and more acceptable for people and not to make it more difficult. People with disabilities have difficulties of their own to face. They must address their own issues as well as dealing with society's biases. The points made by our guests are very valid. I would strongly support what they have said generally and will pursue it to the best of my ability.

**Co-Chairman (Deputy Michael Moynihan):** As we are having difficulties hearing from Senator Davitt we will move to Senator McGreehan.

**Senator Erin McGreehan:** I welcome everyone and give a special shout out to another Louth woman, Paula Soraghan, who is also a great advocate for the Louth accent. It is lovely to hear the Louth brogue and great to hear strong female voices. I met Ms Price before on a call and Nem gave a great contribution to the Joint Committee on Children, Equality, Disability Integration and Youth on assisted decision making and the lack of consultation, and real accessible consultation. I was very disappointed about the assisted decision making Bill. I think we were sold a pup, a pig in a poke on the Bill. We have a lot of work to do to bring it up to scratch.

Returning to the barriers women face, I was struck by Ms Hassett's statement that "for many disabled women, being a woman with a disability is like having a double disability". That is both upsetting and not surprising. The obstacles include financial independence, means testing on a partner, reproductive rights, access to employment, safe access to travel and transport. These are things that we speak about regularly but there is a double barrier, as we know too well. I have a question around representation and having one's voice heard. I heard Ms Soraghan speak about the importance of a DPO and of funding DPOs. What happens if a DPO's voice is not heard? We fund so many organisations in the State but we are not funding DPOs on a proper basis.

I am particularly interested in hearing from Ms Soraghan because she made such an incredible contribution to myself and to the Minister of State, Deputy Rabbitte on the importance of funding DPOs and what that means on the ground for individuals. Then there is the way that is transposed at a local government and national level and the huge changes that can make. I would be interested in hearing from her and all the contributors on the importance of funding DPOs.

**Deputy Seán Canney:** I thank everyone who has joined us for this very important meeting. My concern relates to the means testing of disability payments. I know a disabled man in my constituency who got married and lost his disability allowance because he was married. That has caused him a loss of independence as a man. I met him and his wife and they were devastated. If they knew the consequences, they never would have got married. That is an awful indictment of the system we have. They were so pleased and happy to have found one another and are going to live their lives together but they are being punished financially. That man's disability has not gone away. I am hearing from our guests that when people have a disability, they need support regardless of their means.

I also have a major issue about the lack of transport supports, which the committee has discussed in the past. I am from a rural constituency and understand that people cannot access public transport or taxi services that cater for their needs. It is important that they can get out and about and try to live their lives independently. One of our guests said they feel that transport supports might have been abused when they were first introduced and that people took advantage of them. I would like to hear our guests' comments on the following: do they feel, as women, that they are being punished for the sins of others in that the transport schemes that were there have been taken away or have become dysfunctional and not fit for purpose? Do they feel there is an attitude in the Department of Finance that these schemes have been blackguarded in the past and it is going to make sure they will not be blackguarded in the future but in doing so have gone from one extreme to another? I would like their thoughts on that matter.

I also raise the reliance on one's partner for income support. That does not bode well for

good relationships in any household. The independence of a person, whether disabled or not, is very important. The case our guests have presented is true for every woman in society who has to rely on somebody else for her means. I thank our guests and will listen to their comments.

**Ms Paula Soraghan:** I thank Senator McGreehan for her comments. It is lovely to see her again. All of us who are before the committee, who have given our opening statements and represent disability organisations, are disabled women. We all identify as disabled. We have, therefore, authentic lived experience of what it is to be a disabled person. That is very important.

*(Interruptions).*

**Co-Chairman (Deputy Michael Moynihan):** Ms Soraghan's screen has frozen.

**Ms Paula Soraghan:** -----have that sense of community and belonging that I have with ILMI. I kind of-----

*(Interruptions).*

**Co-Chairman (Deputy Michael Moynihan):** There seems to be an issue with Ms Soraghan's connection. We will go back to her in a few moments. We will go to Nem Kearns next, followed by Ms Price and Ms Hassett, before we come back to Ms Soraghan.

**Nem Kearns:** I thank the members for their insightful questions. I will try to synthesise my answers to touch on various questions because we are pressed for time. If a person is on the maximum rate of disability allowance and earning the maximum allowable under the means test disregard, he or she is still earning less than the minimum wage. More than half of that is going on the average cost of disability. We are asking why disabled people are in poverty. It is because we make them fall into poverty, to be blunt. The system forces disabled people into poverty. It forces us to stay dependent. It does not empower us or enable us to move past that or to try what we can. The cost of failure for disabled people is far too high.

To touch on what the Deputy said, there is sometimes a sense with regard to all sorts of things faced by people with disabilities, from State supports to getting a ticket on Ticketmaster and all other aspects of life, that disabled people are constantly being punished and non-disabled people are possibly exploiting a loophole. We are constantly having to prove our case and offset what someone else may or may not do. It creates a constant fear, stress and othering for disabled people in their lives. The human cost of that cannot really be quantified.

There is considerable financial insecurity and dependency if, for example, a person gets married and has his or her supports based on someone else's income. There is also the human element. It is very difficult to have a healthy and equal marriage or relationship when the other person is entirely responsible for you, as a human, and you have no independence whatsoever. It places a very great strain on interpersonal relationships. While the financial and economic side is important, the human side, which involves constant stress, othering and the diminishment of disabled people, also needs to be acknowledged. We need to create a system that allows disabled people to explore, grow and do what we can. We must not be punished for trying to be anything other than passive and in a corner. It would also create a much better country for everyone. It would also relieve some of the burden on the State. The system as it stands means disabled people must be reliant on support forever because they will not be supported if they try to improve their own circumstances. That is a catch-22 situation that makes no sense for anybody involved in the equation.

**Ms Paula Soraghan:** I apologise; my connection dropped. I thank Nem Kearns for their comments and agree wholeheartedly with what they said. I will pick up where I left off. Since getting involved in a disabled persons' organisation, I have had many opportunities because I feel I have found my community, as a disabled person. I have the impairment label of cerebral palsy but I have realised that cerebral palsy is not the issue that prevents me having opportunities. The issues are the attitudinal and environmental barriers in society. So many more opportunities have arisen since I became involved with ILMI. I work full time and am doing a master's degree in disability equality. I have realised that we disabled people have much more potential than we are made to feel we have by society. I want opportunities for more disabled people. It goes back to what I said earlier and I know Disabled Women Ireland will echo this. It comes back to choice. At the moment, disabled people do not have many choices in their favour or that benefit them. That is true of disabled women. We need to make the changes we have discussed at this meeting and make them a reality. That, of course, includes financial independence. To go back to Senator Seery Kearney's comments about marriage equality, many people do not realise that it is actually an issue for disabled people. Many people are shocked that it is the case. That is something we all want to see changed. It is tied to whether you are in receipt of disability allowance. You cannot live with your partner or get married without those supports being taken away. That is grossly unfair and it needs to be changed. It proves that we do not have the same choices as many non-disabled women, for example. If people want to get married and live with their partner, they should be able to make that choice without fear of their supports being taken away. I believe that needs to change. I wish to emphasise the importance of local DPOs. You are part of a community and get the most out of your community. It does so much for your mental health and well-being. You feel like you are a part of the social change that needs to happen. You realise, as in my case as a disabled woman, that your impairment is not the problem, but that society is the problem and that needs to change. I thank the members for listening to my comments.

**Ms Aoife Price:** I concur with that especially in relation to not being able to live with the person you are in love with. It is a huge burden on many people because of finances. It is a huge issue not to be able to live with the person you love.

The other issue I want to come back to is about consultation. As Nem Kearns said, when we are consulted we are often not told how that consultation will make a change or, indeed, how what we said will not have an impact. Many people now have what we call "consultation fatigue". Consultations are done in an inaccessible way and are not done in the best way. They do not feed back to the participants and are not fully inclusive. When we are doing consultations, first, we need to be included and, second, they need to be meaningful consultations. They should be more like partnerships and should involve working together going forward rather than a one-off consultation. We should be moving away from consultations and moving towards partnerships and working together more long term.

Funding DPOs is so essential, as is building the capacity of the people within the DPO to fully participate and contribute to society. This is very badly needed.

I also want to briefly touch on what I call an education gap. Like many disabled people I know, I had to withdraw from education at certain periods. Therefore, if you go to college, you are older finishing college and are later getting on to the career ladder. The fact that there are so many factors really needs to be considered as well. It is multifaceted and that is really important. I want to highlight that people sometimes have to take time out from education and this delays them. They are not on a par with their peers in terms of career progression and dif-

ferent factors like that.

**Ms Nicola Meacle:** I want to speak briefly to the importance of the DPOs. For decades, disabled people have had professionals, experts and service providers talk on our behalf. Sometimes we might be involved in a tokenistic fashion. Now we are the people with the lived experience and that makes us experts in what it is like to live as a disabled person. DPOs are the spaces where disabled people are empowered and trained to go into spaces where decisions are being made that affect their lives, such as in housing etc. DPOs are also the spaces where people can build up solidarity and support each other, in terms of confidence building to go into those spaces. For many years, disabled people learned to be passive recipients of care and DPOs challenge that.

On the lack of personal assistance supports for people, not only does it create stresses on managing relationships but it also creates family stress. There are times where disabled adults are relying on their children to provide for their needs that are not met by the inadequate personal assistance support service. When there is a person in the house receiving carer's allowance, and where there is an adequate personal assistance support service, it benefits the carer who can perhaps take up employment, which would save on the cost of the carer's allowance, and the disabled person can use their education to gain employment. In Cork, I know people who have received supports up to the end of third level education, including access to personal assistance and assisted technology etc. Once they graduate, they reach the edge of a cliff where there is no support and they are at home unable to utilise their master's degree. I know another person who, not because a love of academia, chose to do three master's degrees because when they left college, there was a 40-hour gap in their week in which they had been receiving support from a personal assistant during college hours.

**Ms Amy Hassett:** Most points have been covered, but I will pick up on two or three small points. We share Senator McGreehan's concern about the Assisted Decision-Making (Amendment) Bill and the lack of consultation and accessible consultation around that process. It is not just the Bill that we have concerns about. We need to be very careful around the codes of practice and operation of the Decision Support Service, DSS, and around the consultations around those codes and operations, as there has not been a lot of accessible consultation with disabled people on those systems.

It is also important to bear in mind that for matters such as assisted decision-making, there is a huge gendered component. In addition to experiencing discrimination and bias because of being a disabled person, there is also a gender bias. We know that it exists and it is a significant concern we have. In relation to the gendered aspect, access to medical cards and medical expensive also have a gender dimension. There are different costs associated with conditions that tend to be gender specific. Access to medical cards is, to a large extent, means tested, which is creating massive issues for disabled people in trying to access the healthcare they need.

When we call for resourcing and funding DPOs, we also are talking about building capacity. What we mean concretely with that is giving disabled people the training and information they need in order to do consultations. People do not pick that up off the ground. There is a system and a structure in place and it is something professionals have knowledge of that we do not. When we talk about funding and resourcing DPOs, we are talking about those practical things, like paying for ISL interpretation or a Zoom account. It is about enabling us to create spaces that are accessible to a wide range of disabled people. That is the boots on the ground impact of funding and resourcing DPOs.



**Deputy Holly Cairns:** I thank all the witnesses for coming in today and helping us to understand the intersectional issues around disability, gender and finance. It is difficult to know where to start because so many issues have been raised. It is relevant to International Women's Day. When speaking on it in the Dáil this week, I referred to the tokenism of speaking about it on this one day. It raises awareness and we need that but it is the other 364 days of the year that make a difference. Speaking about women's issues on one day and disability issues on another, while talking about everything else the rest of the year, will not make a difference to people's day-to-day lives. That is where the real problem is. Those tokenistic days cannot feel like lip service.

One of the things that was touched on quite a lot was the cost of disability and social welfare. We learned recently that when applications for disability allowance are refused, over 50% are granted when people reapply. It just shows the over-restrictive approach from the Department of Social Protection, which is basically telling people they have to apply, be rejected and reapply and then they will get it. That plays out in so many areas of disability. That transpired at a meeting of the Joint Committee on Disability Matters last week but the same happens when schools apply for SNAs. When they are turned down, 50% of those that reapply get it.

There are so many issues I would love the witnesses to elaborate on. They touched on the family courts, disabled women having children, access to transport and issues around diagnoses. There is no understanding from this Government of what a rights-based approach is. There is no understanding of how to take that approach. That is not happening in Ireland at all. There is one thing I always come back to in these sittings and it is important to keep saying it even though I sound like a broken record. We need to ratify the optional protocol to the UN convention because then people will have a legal entitlement to rights. It is very clear that the Government is not just going to allow people to exercise their rights. It must be held accountable. Unfortunately, that seems the only way we can do it. Other countries have ratified the optional protocol and it is a disgrace that Ireland has not. We were the last country even to ratify the convention itself. We need to make that point over and over about ratifying the optional protocol. The Assisted Decision-Making (Capacity) Act 2015 was constantly used as an excuse not to ratify it and we are coming to a point where that excuse cannot be used any more.

I want to ask specific questions about disability, gender and finance that will help to inform the committee going forward. Ms Hassett spoke a bit about the Assisted Decision-Making (Capacity) Act. What is its potential impact on financial independence? I ask for a clear answer on that. In its current form, will it enable greater independence or does Ms Hassett have concerns about elements of it?

The Central Bank is revising its code of practice in order to ensure people with disabilities - I was going to say vulnerable people but Nem Kearns and Ms Soraghan have highlighted that these are people who are made vulnerable by society - can gain access to mainstream financial services in light of the Assisted Decision-Making (Capacity) Act. Has the Central Bank engaged with the witnesses as part of this process? What consultation should it be conducting with people and organisations?

The capacity of individuals with disabilities to access credit has been identified as an issue. Credit unions are an important source of credit given their inclusive culture and their accessibility in communities, particularly rural ones. Current limits on loans are so restrictive. I ask the witnesses to comment on that and on the types of credit facilities disabled people need. Credit unions are more accessible in general, even geographically, but because of the rules they have to abide by they cannot currently give loans for housing, unlike other organisations, and that is

something they are keen to be able to do.

**Senator Fiona O'Loughlin:** I thank the Co-Chairmen for this initiative. It is great to have the two committees together. We might be able to make some progress on this matter. I thank the witnesses for their very powerful testimonies about their lived experiences. That is what we as a committee want to hear. We want to hear about the obstacles and challenges people face in their daily lives, in order to allow us to make recommendations.

The committee is very aware that having access to even a small income and being able to control it is so important for people. That is an essential, basic, daily need. Without being able to manage their own money, people can lose independence and dignity. What are the witnesses' key recommendations for developing a rights-based financial services provision that will enable independent living? In the submission on Article 28, the issue of means testing disability payments and supports came up. This creates an enormous dependence for disabled people on their partners. It brought to mind a wonderful young woman and mother I know. She is married, has two children and her husband has a good job, although he has to be away quite a lot with it. I have seen her in her wheelchair with her two children walking beside her to get to school. As the disability allowance is means tested, she has no form of her own money, even to buy personal products or sanitary products. She finds it incredibly humiliating that she has to ask her partner for money for these things. We all know the extra cost that comes with having a disability anyway. It has been noted that the cost of a disability is generally between €9,482 and €11,743, due to the additional costs associated with mobility, transport, communications and so on. I have a real concern about that. I am interested in hearing more about the cost of disability and how it locks women into consistent poverty and financial dependence. They sometimes cannot afford essential services because the cost of disability is not reflected in social welfare. I ask the witnesses to talk about the fact that these payments are means tested.

I would like to hear more about developing personal assistant services, which would enable people with disabilities, and women in particular, to take up paid employment. A UN report showed that while Ireland has a low level of employment for people with disabilities - one of the lowest in Europe - men with disabilities are almost twice as likely to have a job as women with disabilities. That is something we have to target. Women with disabilities often experience unequal hiring and promotion standards and unequal access to training.

**Ms Amy Hassett:** There was a lot there, so I will go through it point by point. On the costs of disability and the fact many disability allowance applications are rejected on the first attempt, I do not find that surprising. The disability allowance system is complex and convoluted, and the process of getting together the appropriate documentation in sufficient time is very difficult and stressful, whether or not the person requires reasonable accommodations. It continues to be a stressful system even once the person has successfully applied for it and is within the system, given that any earnings he or she makes will have to be reported back to the system and the person has to re-engage with the system continually. That involves a significant cognitive load, time load and administrative load, and it is very stressful and complex. It is not entirely clear what documentation you are supposed to send where. It is not surprising, therefore, that so many applications fail on the first attempt and are accepted on the second. My experience is an example of that.

On the costs of disability and the gendered aspect, we have heard much about how disability can be quite costly and I do not need to restate all that. Nevertheless, the cost of living can have a gendered aspect too. There are certain things that gender minorities have to buy that other people do not have to buy. Deciding where we live, for example, and how close we should live

to public transport are all considerations that gender minorities have to take into account, which men may not have to. That should not be the case but it is.

On the broader issue of whether assisted decision-making will enable financial independence, the assisted decision-making system is an improvement on wardship but it will ensure disabled people will have more financial independence only if it is interpreted and amended in a human rights-compliant manner, and we have concerns about that. As the system has been designed and laid out, there is a greater focus on providing people with supports to make financial decisions, if we take that specific context, but there remains the provision for a person's capacity to be tested and that can create a system whereby people can be very vulnerable. It really depends on how we move forward and we have concerns, based on what we have seen, as to whether that will happen. It probably requires a wider conversation and we will happily continue to work with the committee on that if its members wish. It is a big issue.

On how we can make financial services rights based and accessible to people, we need to look at this in an holistic sense. Currently within the financial system, there is a strong emphasis on vulnerability, and huge swathes of people are categorised as vulnerable for very medicalised and somewhat arbitrary reasons, and that too is a big issue. In the Central Bank's codes of practice and documents of this nature, for example, there is very little information on supportive mechanisms or on reasonable accommodations. In fact, if someone needs reasonable accommodations, he or she will be automatically classed as vulnerable and that is just not appropriate. Nem spoke about how vulnerability is not an inherent characteristic of any individual.

As for whether there has been any consultation in respect of these codes of practice, we are not aware of any having taken place with disabled persons' organisations. In order to make them rights based, we need to examine how we can introduce reasonable accommodations as support mechanisms and how we can train people who work in financial services to be supportive and helpful to disabled people and to enable us to make financial decisions and interact with the entire financial system.

**Ms Paula Soraghan:** I echo what Ms Hassett said. I have been in different spaces with many disabled people when they were experiencing financial services. For a person with a visual impairment, for example, there are not many accessible ATMs throughout the country and even less so in rural areas. I have spoken to two people who have a visual impairment, who come from two different areas of the country. They say that even in Dublin it is an issue because the accessible ATM they would be able to use is located inside a building, which is an issue because it is not accessible to them at all times, every day of the week. We need to examine how to make every ATM accessible to everybody. If a person with a visual impairment needs to withdraw money at, say, 8 p.m. on a Sunday, why should he or she have to give his or her bank card to somebody else? That person will then need to know the other person's PIN, which can raise further issues relating to the fact they face barriers that other people do not. Such issues can take away people's financial independence.

All this is linked with the personal assistance aspect. Independence is not about doing everything yourself. For Independent Living Movement Ireland - I am sure Disabled Women Ireland will echo this - independent living is about disabled people having the choice to live their lives the way they choose or see fit, whatever that looks like. Obviously, they must be mindful of how their impairment or condition affects their life, but it is about them having those options to live life as they wish. Many disabled people, unless they are involved in the disability rights movement or a disabled persons' organisation, will not know what personal assistance is. They may not know the difference between a carer and a personal assistant. To clarify, a personal as-

sistant, which is not the same as a carer, is a role where the disabled person is the employer and the personal assistant is employed by that person. It is not that the personal assistant cares for the disabled person rather than the disabled person delegates tasks in order that he or she can, say, go shopping for groceries or go to the pub. Such people are then able to live a daily life how they want and not have to wait for a carer to come in, get them out of bed in the morning and put them to bed at night. They are not restricted. They have the options to make choices to live their lives how they wish.

The issue of accessible taxis and other forms of transport may be a bigger issue in rural areas than elsewhere. As Ms Meacle said earlier, transport is one of the pillars of the independent living movement. It is a big issue and it feeds in to the social isolation of disabled women. Many of them cannot leave their houses when they want to, as was an especially big issue earlier in the Covid-19 pandemic. They may not be able to easily get out and socialise, see friends or go about their day, and they may have to book a taxi for which, in many cases, 24 hours' notice has to be given. There are only two accessible taxis in the entire area of Dundalk, which is a big issue. This needs to change. I have heard from other disabled people that wheelchair-accessible taxis have been used for other purposes such as school runs rather than for what they are meant to be used for. A disabled person might book such a taxi, therefore, and it might end up being cancelled at the last minute. This links in with the broader costs of disability. These taxis are much more expensive than a standard taxi. That is a huge issue because if a disabled person is on disability allowance alone, and if they needed accessible taxi perhaps twice a week, this will seriously eat into their disability allowance. It will mean, unfortunately, that a lot of people with disabilities are actually trapped in poverty. We really need to look at going back to the rights-based approach and engaging more with disabled persons organisations, DPOs, and listening to those people with a disability who have the lived experience, so that we can make changes.

On the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, unless one is involved with a disabled persons organisation or has knowledge of disability rights, many disabled people do not know what the UNCRPD is, and particularly those people who may have been institutionalised due to the special education system, be that in the past or in the present. A lot of people do not actually know what the UNCRPD is or how it could best help them in their lives and how it can help them to fight for their rights. The UNCRPD is a very valuable and fantastic document in theory, but unfortunately it has not been sufficiently implemented. We certainly need to work towards that.

**Nem Kearns:** I will touch on a couple of points, just to mop up between Ms Soraghan and Ms Hassett's comments. There are a few aspects. There is potential for the Assisted Decision Making (Capacity) Act to increase disabled people's ability to make their own financial decisions. As Ms Hassett has said, there are a lot of concerns in that regard and it would very much depend on how it is implemented. It will take a commitment on the other side also, because there is a lot of inaccessibility in banking and in financial services. There is also the whole idea of capacity: a person either has it or does not. This does not work for disabled people. For example, I am dyscalculic. This is not really recognised but it is hugely impactful when a person is trying to deal with finances and numbers. I am in the weird position of being a former bank manager. I have seen from the inside how there is absolutely no provision whatsoever. The only thing now being considered is this idea of capacity or lack of capacity. It seems that the focus is just on letting more people make their own decisions rather than supporting everybody to be able to navigate and make informed financial decisions. I had a tax form to fill in, for example, and there were very blaring things such as the legal and financial penalties if I was to

make a mistake. When I called up there was absolutely no support available. I asked if someone could talk me through these figures and I was told “No, not at all”. It is those little things and those day-to-day things that we need to put in place, as well as whether it is just capacity or no capacity.

There are other issues around the credit side of it. This is completely anecdotal, but I and a lot of other disabled people find the community-based credit unions are much more accessible and more supportive. Obviously, that depends on the credit union. There may be a way that the finance committee, or someone else in the right position, could look at a number of issues around the schemes and grants available. Leaving aside the horrific and restrictive application processes, a housing adaptation grant or other such grants are generally drawn down after the capital outlay. Given that we are talking about a population that is far more likely to be living in poverty, this is very impractical and very limiting. Even if people fulfil the criteria, this system disadvantages the people who need it the most and who do not have any money or any savings to pay upfront for the accessibility that they need. If a person does qualify, he or she is limited by what he or she can afford right that minute and the person is not able to get what is needed, because of the draw-down afterwards system. It is about looking at and examining how the system works in each area, asking who does it exclude and who does it disempower and just changing it so if a person qualifies for one of these grants the money is made available to get the accessibility that needs to be put in place

There are other issues around reasonable accommodation and assistive technology, of which there is not enough in this country. Part of this is how much of the assistive technology is linked to the person’s employment. When we think about it, this is incredibly disempowering also. For example, a blind person might have access to screen-reading software through his or her college or job. Once they leave college or that job they do not have it and they cannot even read job specifications to apply for employment. It is all very broken up and does not actually look at what it means to live that way and to live that life.

I wish to make an unrelated point, which I had forgotten to make earlier. The Minister of State, Deputy Rabbitte’s, announcement yesterday of the research into gender-based violence is extremely welcome. We would like to have it on the table that this is something that would very much need DPO involvement from planning through to the delivery stage, just to make it very robust. We have had other research, while not enough, on gender-based violence but it has not resulted in any change. It is crucial now to make sure that it reaches the people it needs to reach, that it is accessible to everyone who needs to be involved, and that it is informed by, and put through the lens of, making actual changes and not just counting the numbers. We know that the numbers are astronomical. There is a huge body of international research, and there is a small amount of research in Ireland. The question is no longer about what is the rate. The question now is what we do about it. This needs to be front and centre when looking at any action to be taken.

With regard to personal assistance and financial empowerment there have been discussions about placing the home help service on a statutory basis. Obviously, there is a need for home help, which itself is under served, but home help is not a tool and is not something that can empower financial independence for disabled women or for anyone. It provides a service but home help does not help a person get to his or her job, it does not help the person set up the laptop to answer emails, and the disabled person has no control over what services he or she gets. Home help cannot help a disabled person go to a job interview or anything like that, but a personal assistant does. We really need to be investing the resources into personal assistance



rather than putting more money into home help. We need to get more ambitious. There seems to be a feeling that we will not be able to get a national right to personal assistance and that we must win the home help fight first. It feels a little bit like the marriage equality referendum in that regard, whereby there were two camps. One was trying to go for civil partnerships because “we will never get full equality, and we must do this first so that people will get used to it, and then we can try the other things that are actually needed”. Sometimes it feels as though the conversation around home help and personal assistance is the same, and a recognition that while personal assistance is what is really needed, it is too ambitious so we must get there incrementally. We would very much argue “No” to this. We know this is what is needed and it can make such a day and night change in people’s lives. This what we should be doing and that is where we should be putting our resources.

**Ms Nicola Meacle:** I commend Nem Kearns’s comments around independent living personal assistance, PA. There needs to be a statutory basis for PA services. Currently it is arbitrary and the eligibility criteria is different for every CHO area. If I have a home help, for example, that home help can go to the shop for me but I cannot go to the shop with the home help. This could be a whole discussion in itself. With regard to people who require a PA to go to the bank, in terms of privacy and finances we all like to have our own personal finances, the closure of banks, especially in rural areas, has been a real loss. I know of people who would have built up a relationship with the people who work in the bank. That member of staff would make accommodation to work with the disabled person individually. Even though I know they really do not do that anymore, they would make that accommodation. For anyone making the transition from home to living on his or her own or living independently with access to personal assistance, training around budgeting is crucial. It is not just disabled people who need training on budgeting. Any young person making that transition from his or her teens to adulthood needs training on managing finances. Many organisations have training courses that are in plain English and are user friendly.

The credit unions, obviously, have more of a community-based ethos and there are micro-loans. However, the interest rate is much higher. The purpose is to prevent people from going down the route of moneylenders. Unfortunately, the interest is higher than a regular loan and the amounts are quite small.

With regard to housing, if a disabled person is in a position to save up for a deposit on a mortgage, he or she may reach a stumbling block when it comes to life insurance. The cost could be prohibitive, if that person is lucky enough to secure life insurance.

**Co-Chairman (Deputy Michael Moynihan):** From the Oireachtas Joint Committee on Finance, Public Expenditure and Reform, and Taoiseach, we have Deputy Jim O’Callaghan, followed by Deputy Murnane O’Connor.

**Co-Chairman (Deputy Jim O’Callaghan):** I welcome all of the guests. It is very useful that we have a meeting of this joint committee because a discussion about disability matters without a corresponding discussion about the financial supports that are required can lack realism. I will address a question to Ms Meacle or Ms Soraghan. I am a member of the Oireachtas Joint Committee on Education, Further and Higher Education, Research, Innovation and Science and from that committee am aware that your financial independence and future earning ability are significantly affected by whether you have been to or completed third level education. If you have been to or completed third level, there is a much higher chance that you will have much greater financial independence in your life. What support does the State need to put in place to ensure that more women with disabilities access and complete third level courses?

**Co-Chairman (Deputy Michael Moynihan):** We will hear Deputy Murnane O'Connor and then we will go to our witnesses.

**Deputy Jennifer Murnane O'Connor:** I was at another meeting but I have been back for a while. I thank everyone. It is very important for us to make that change. Ms Kearns spoke about gender-based violence and I spoke to the Minister of State, Deputy Rabbitte, who will conduct research into gender-based violence against women with disabilities this year, which I welcome.

As previous witnesses have said, it is important that people with a disability are at that table and that we listen to people who are able to give us proper information and tell us what is happening. That needs to be part of it going forward. However, I know the Minister of State is committed to this. I am fully supportive of it and we all need to make sure we give support and get everybody on board. I was listening to Senator O'Loughlin speak about barriers to women gaining employment, which is another serious issue we need to address.

Housing adaptation grants were brought up, which I know about from my local authority. The rigmarole one has to go through is unacceptable. There needs to be a system without barriers to those grants. There also needs to be a system where people who have a disability and who are on the local authority housing list are housed quicker. It is another battle.

All the local authorities seem to have different policies. I have brought this up before with the Cathaoirleach and the committee. We have a duty to see that all local authorities have the same policy mechanism and that a certain number of houses are built every year for people with a disability. The barriers I go through with the adaptation grant are unreal. I completely understand where that is coming from.

I am working with some wheelchair users in my area. I am very close to them. What is happening in rural areas upsets me very much. Bagenalstown, which has a fabulous train station, is one example, as Irish Rail no longer mans the station. It has taken the stationmaster away and he has now gone to a different job. We now have a situation in rural train stations whereby there are no toilet facilities for wheelchair users or elderly people. The station is not manned and if it is raining, one cannot go inside.

We are taking backward steps. A lady who was taking the train into Carlow contacted me the other day. She had to go down to the pub across the road to use the bathroom facilities. We have to make sure, in 2022, that we do not take facilities away from people with disabilities or wheelchair users. I have significant issues with that.

I work daily with carers and family members who are applying for carers. It is a constant battle with the Department. There is no training or extra supports for family support for carers. The whole system needs to be revamped. I thank the witnesses because as they have said, when one is in the position of fighting hurdle after hurdle, one can reach the stage of breaking point.

Another issue is mental health issues within the sector. We have all seen with Covid how everybody was impacted, including people with disabilities. We did not put enough services out there. We have to make sure we are very mindful of people's mental health. The committee is absolutely dedicated to doing anything we can to change the system and to giving everybody a say, especially those with disabilities who should be empowered and sitting at the table, in making those changes. Changes can only come from within and from people who are affected by them.

**Co-Chairman (Deputy Michael Moynihan):** Does Ms Soraghan want to take Deputy Jim O’Callaghan’s point? Ms Price has also raised her hand.

**Ms Paula Soraghan:** I will take Deputy O’Callaghan’s point. It is a very good point. While I have gone to third level, the issue is that disability is still seen as a medicalised issue in education. It is not seen as a social issue. When you are in primary and secondary school, for example, there is no streamline or portability of services in terms of the supports you have or need. I was fortunate to get the supports I needed, such as a scribe when I was doing my exams or a note taker when I was in class. However, many disabled people do not have that. It can depend sometimes on what their impairment is such as the impairment labels of dyslexia or Down’s syndrome. People can be treated differently depending on their impairment level and different expectations can be put on people, as a result. To answer the Deputy’s question, portability of services and supports is needed. If somebody has supports in primary and secondary school level and he or she wants to go third level, those services or supports need to be available to him or her in third level education. Much of the time, that is why many people do not pursue third level education.

Many people simply do not feel they have the confidence to pursue third level education. That can be internalised by disabled people in that they are told they would not be able to do this or that and college might not be for them. That can depend on what somebody’s impairment label is, as that can also cause issues.

To go back to what my colleague, Ms Meacle, said earlier, many disabled people get the necessary supports that they need in college, for example, a note taker or personal assistant, but that stops when they finish college. That should not be the case. The supports need to be portable and must be streamlined across the country and across all local authorities so that disabled people do not continually come up against these barriers.

To bring it back specifically to disabled women, I have been in a space where there is a young disabled woman who got a wonderful leaving certificate and she is in college now but she has home help. She has to go to bed at 9 o’clock every night. This is a young girl who is in college. She did try to get the time changed so that she could enjoy her social life in college, but it was denied. That is a significant issue, going back to the isolation disabled women face. She is simply not having the same experiences as her peers, not because of her impairment label but because of the systemic barriers that she is up against. Whereas, if she had a personal assistant, that would be a completely different story. It is not just young disabled women; I know of an older disabled woman who does not have a personal assistant, as far as I am aware, but she has home help and she is put to bed at 8 o’clock every night. It is a shame because there is such restriction there and it has such an impact, going back to what was said about mental health and emotional well-being. Disabled people just do not have the same choices and quality of life. The issue is not someone’s impairment but the social consequences of having an impairment label. I thank members for listening to my comments.

**Ms Aoife Price:** I want to come in on this because it is something I am particularly passionate about. I feel very privileged to be at the level of education that I am at, but it was not a straightforward road. We need to look back to much earlier. For example, when I was starting second-level education, my parents were told that I should go into a lower stream class, which would have meant that I would never have got the opportunity to properly go to third level, certainly not on the path I went on. There are ways that society still thinks about disabled people. If it was not for my parents’ belief and fight, I do not know where I would be or what I would be doing today. Education helps to level the playing field for everyone, in particular

for people with disabilities. High-level education is very important, but we are not very well represented in higher education, in particular when it comes to postgraduate education. That is a significant issue. Disabled people are not represented in postgraduate education and that must be addressed and supported.

On supports, monetary support is very important for disabled people to continue in higher education. On top of medical costs, the cost of assistive technology is a major expense. There are disability supports at third level and some of them are fantastic, but they vary from college to college. I have attended three universities at this point and each of the supports has been quite different and unique. They do not all provide the exact same supports in the same way. There is a lack of streamlining of supports at third level. For example, when I was in Trinity College Dublin, there was a very good occupational therapy service for students experiencing mental health difficulties that I really benefitted from, but now I am in Galway and more of the supports are geared towards dyslexia and I am also dyslexic. My point is that the services need to fit everyone's criteria in all the universities.

I also want to make a point about the fact that when I was studying for my master's I changed from a full-time course to a part-time course. Many people with disabilities have to consider part-time education but there is not enough support for people in part-time education. Many disabled women, in particular, choose to do part-time education.

I echo what Ms Soraghan said about personal assistant supports and supports to socialise and attend college and do all those things. That is important. There must be a focus on education and, in particular, a progression to higher-level education. When they get there, students at higher level must be supported, including to go on to postgraduate education if they choose and that is something they want to do. We have seen changes even in the past year. It has been brought to our attention through Catherine's Law and the disability allowance. Education contributes to a levelling of the playing field, and it is important that we support all disabled people, in particular disabled women, to progress in third-level education. We must support them to finish, because often there is a problem with people dropping out because they do not get the supports when they start. That could have happened to me on several occasions, but I had the support to continue the third-level journey. In one instance, I took a year out of college when I did my degree and in the second instance I changed from full time to part time. At the same time, I had the full support of my parents to do this, economically. I am privileged to be from a family that can afford that, but many families cannot. They are very important points to consider. Education can be a leveller, but we need to support disabled students within higher education.

**Ms Nicola Meacle:** Most universities have a programme where they actively go out to students in secondary schools in marginalised, economically deprived areas and get them to go to the campus and get a sense that they could aspire towards being there and belong there. Perhaps a similar mentoring or big sister, little sister programme for disabled students at secondary school level would be good. A disabled student who is already in third level could talk to a disabled student at secondary level and encourage them to aspire towards third level. That said, going on to third level is not for everyone. There is a range of PLC colleges that would be excellent stepping stones to other courses in further education.

As I said, further education does not suit everyone and there are other options out there. There is a growing emphasis on apprenticeships in Ireland, for example, which are no longer limited to the trades. It is possible to do an apprenticeship to become an accountant or actuary and for other occupations. Practical, part-time education may suit some disabled people more

than others. As has been noted, having family support, including economically, is a big factor. This may be an issue, especially for students who want to do a course that requires them to move away from home. That is a very expensive endeavour for any family.

Ireland has a good track record on lifelong learning. If people do not go straight to college from secondary school, it does not mean their opportunity to avail of further education is over. All colleges and universities in Ireland are very open to mature students and they value and recognise their experience. Most third level institutions are very supportive of disabled students. Many universities have a disability support office that works with disabled students to support them. They are very good at facilitating students, for instance, to do a full year over two years if they have a disability with which fatigue is an issue.

There is a discussion going on around increasing the number of disabled women in third level education and getting people educated up to degree and master's level. However, a point to note is that when people finish their course, there is a 40-hour gap in their week in which they do not have access to the disability assistance support or assistive technology they previously had.

**Nem Kearns:** I want to tease out the gendered aspect of these issues. When it comes to neurodivergencies, which include autism, ADHD, dyslexia, dyscalculia and lots of others, there is a huge gender gap. Most gender-minority people with autism, ADHD and all of these things do not find out about it until they are adults. That means they go through their school life absolutely unsupported and unrecognised. This is due to gender biases. There is not a different level of need but just a different likelihood of such needs being picked up by the system. We need to look at that. It is very difficult for people to catch up on their education at the age of 30, when they have been completely unsupported through primary, secondary and every other level. It also is very difficult to overcome a history of stress and failure associated with being unsupported.

An issue that ties in with this is the fact that women are much more likely to go unsupported in education for a far greater part of their lives. For example, I was diagnosed with two neurodivergencies in college. I was extremely lucky to be diagnosed and extremely lucky to go to a college that could help me with that because there is absolutely no way I would otherwise have been able to afford to seek that diagnosis. Again, there is no facility for diagnosis under the public system for people beyond school age. Certainly, there was not such a facility when I was that age. I would have been looking at thousands of euro just to get diagnosed.

Another issue we need to look at, which really affects the inequality women and gender minorities face, is that people do not necessarily get any information. When I was diagnosed with ADHD and dyscalculia in college, I was not given one sentence of information about what either of those conditions is and what they mean, never mind being told what supports were available or which supports might help me. I ended up dropping out of college. I really feel that if I had known then what I know now, I would not have done so. I loved college and got the highest mark of everyone on the entire course for some of my work. It was not lack of ability or commitment that led to my dropping out; it was lack of information on how to navigate my situation. That is something we need to look at.

There also are gender biases in terms of the things that are supported. We have mentioned fibromyalgia, which is nine times more common in women but is not recognised in this country. It is an incredibly debilitating condition but because it is not recognised, it is not supported. We have a terrible history as a country - in fact, it is an ongoing issue - of not giving adequate recog-



dition that mental health issues are a disability and fall under the remit of the UNCRPD. We are not treating mental health that way in most of our approaches to it. Again, mental health issues affect women more than they do men. There are variations for different conditions and experiences, obviously, but women are being unsupported because of the approach at State level to certain impairments they are more likely to experience. As a country, we need to revise our list of what counts as a disability because it is horrifically out of date, it is not UNCRPD-compliant and it leaves people with absolutely no recourse or support. Most of those people are women. We have an inherited gender bias in this area and we need to go back and unpick, challenge and change that in order move forward to a more equal future.

**Senator Alice-Mary Higgins:** I thank the witnesses for their contributions. I have an overlap with another committee meeting that also is looking at gender equality and the question of recognition of care in the Constitution - not necessarily just carers but the whole area of the provision of care. That issue is part of an evolution that is needs to happen.

Reference was made to the difficulty of getting a diagnosis, with fibromyalgia and ADHD being mentioned specifically in that context. It seems to be the case that for women, in particular, there is huge pressure to manage their condition. There is an idea around not creating difficulty or stress and all of the pressure that goes with that. We know that women in general encounter that type of attitude in accessing supports from the health service. To what extent is that problem compounded for women with a disability? Rather than people getting the supports they need to reach their full potential and do everything they want to do, is it more of a case of their condition being managed to a lower level of ambition? I am interested in that aspect because I know it is an issue women experience in general in regard to the health service, that is, the downplaying of problems and the pressure to self-manage their situations. I am wondering how that may be compounded for the witnesses in their situation.

I also am interested in the economic aspect. I was really struck by the example given of people dropping out of college and the pressure in that regard. We know this type of situation arises in the case of employment as well. Are there points at which people feel they must make a choice where, for instance, there are family carers involved? A person's family might be getting carer's supports and the person may be getting disability allowance. The support may be available as one package for people. How does that fit in with other supports, which may be more nuanced, that allow people to pursue education and employment, such as the provision of personal needs assistance? I am interested in the dynamic whereby there seems to be a very binary position that comes into play. It seems that this is a position that women with a disability get put into often, as do people with a disability in general. However, this particularly affects women, in situations where financial supports are available not just to them but to their families, and where one version of their disability is framed. On the other hand, they might want to try employment or education while keeping their supports in place. Could the witnesses comment on those points? There is useful information around the specific payments, specific measures and policies, but could they comment on those dynamics? I think they can bring a unique understanding to that.

**Co-Chairman (Deputy Michael Moynihan):** Would anyone like to come in on the Senator's points? We will start with Nem Kearns.

**Nem Kearns:** I thank the Senator for her questions. There is a valid, interesting and nuanced discussion to be had on this. I do not know how familiar members are with the research from the last three years. A huge report on gender bias in medicine found unbelievable discrepancies there. As we mentioned, many conditions that mostly affect women are treated with dismissal.

In general, they are not recognised. These include fibromyalgia, myalgic encephalomyelitis, ME, and others. The Senator also mentioned the delay in diagnosis. There is a 12-year average difference for men and women with Ehlers-Danlos syndrome, EDS. This is a whole-of-system impairment and has massive effects on a person's life. Women are just dismissed. This is also of huge relevance for disabled women, whereby the mere fact of biology leads to much dismissal and pain. It is just supposed to be put up with. Oestrogen affects many different impairments, from bone formation to ADHD. The menstrual cycle is an impactful thing. It is recognised as such to a certain extent for other women. However, if you are disabled, you just considered as less female, or something. I am not sure what the logic is. There is a lack of knowledge and there is also a complete dismissal of the importance of this.

There is an idea that you can be "coping" - which is a word that is used a lot - but not thriving and not empowered to live your best life. Again, to give a personal example, I was struggling very much recently. It took more than a year, as well as a supportive GP who fought for me, to get to see a specialist to try to get medication for my ADHD. I have never had the opportunity to try it. I went to them and told them about how I was unable to do my job and unable to perform my daily tasks. It had an unbelievable impact. If I did not have such a supportive employer, I would basically have had to go back to being unemployed. The specialist actually told me, "But you are not in danger of dying. You are coping, so I am not going to give it to you". They also said that work was not as important for women as it is for men, because men's point of pride is their work.

While I am loathe to speak of personal stories, sometimes that is all we have. We do not have the data to back it up. These stories constantly arise when disabled women talk to each other. It comes back to that. It is not even a double whammy. It is a specific interplay between gender and disability. Women are not supposed to make a fuss. Women are supposed to smile, to push through it and to cope. We are not supposed to have ambitions for our lives to the same extent as men. It is not as important, and we should be perfectly content with being in the domestic sphere. We have lower ambition for women in general and we have much lower ambition for disabled people. That in turn translates to our ambition for what equality and ambition for a disabled woman's life should look like. Those are issues that need to be challenged.

To go through the supports, as the Senator said, there is a tension between the two types of support. For example, someone might have disability allowance, and someone in their family might get carer's allowance. I will also mention that carer's allowance is well below the poverty rate and does not cover the costs. Most family carers have to pay out of pocket to cover unmet disability-related costs. That needs to be looked at. Nearly half of family carers are themselves disabled, so this is another area that needs to be focused on. There is an issue whereby if you try to be anything apart from dependent, you risk losing everything. The system is not set up to encourage, to empower or to let people take the chances they need to take to improve their lives or change their circumstances. There is no transitional support. You are left very much to fall off a cliff edge.

This falls back to the system which is overly medicalised. While "confrontational" is not the word I am looking for, it often feels as though the system is confrontational with disabled people. There is always that aspect of having to prove yourself. It feels like if you do anything that does not fit into the lowered expectations of a disabled person, everything will be taken away. This is because of the idea that if you can do this, then you are not really disabled. That is where we will find much tension with people trying to pick up employment and take up part-time work. There seems to be a perception that if you are able to do certain things, you do not

fit into the stereotype of a disabled person and their limitations. Therefore, you do not need support. I know that this is less concrete and figures-driven, but it is part of the conversation we need to have. We need only look at why we do not expect or support disabled people to thrive, as well as the limitations that places on our lives.

**Co-Chairman (Deputy Michael Moynihan):** Would Ms Hassett like to comment?

**Ms Amy Hassett:** To follow up on what Nem Kearns has said, the relationship between families and disabled people can be fantastic. It can also be a very tricky one. We need to bear in mind that many disabled people have no choice other than to live with their families and to continue to live with their families. That can create challenging dynamics between the financial independence of a disabled person and the financial situation of the family. That can create some quite dangerous and quite toxic situations for disabled people. This most certainly requires much more scrutiny in order to ensure that disabled people have financial independence, as well as to ensure that disabled people only live with their families when they want to. That is not the situation we have now. Oftentimes, there is no other option.

In relation to healthcare, Nem Kearns captured just about all the points. I will also say that there is a financial aspect to that, given that this is today's topic. When we disabled people interact with the healthcare system, and particularly as disabled gender minorities, we have to combat two sets of biases. There is a lower expectation for disabled people's health or, as Nem Kearns said, about this idea of "coping". It is enough if a disabled person is coping. What is determined to be "coping" is very rarely decided by the disabled person. We also know that this happens to women and gender minorities when they are entering into healthcare situations. There are lower expectations for them in terms of what constitutes living well, being healthy and feeling good. If you are a disabled woman going into the healthcare system, you are up against both of these biases. What is the financial impact of that? For many of us, we have to try as best as we can to rely on the public system, which can have incredibly long waiting times and there are not many options. If you come across a consultant through the public system who holds some biases against you, there are few options to switch to other consultants or to find better care elsewhere. This means that many disabled people - and I know this from personal experience as well as from the experiences of people around me - have to pay. Many disabled women find themselves having to, in effect, go to a series of consultants in order to get the support they need in a non-biased and non-demeaning way, and find a consultant, GP or any healthcare practitioner who will see their goals the same as they do, to level the playing field. That has a significant financial component because going to see consultants and different healthcare practitioners privately is very expensive. This gendered component in addition to the disability component means that disabled women have to do a lot more shopping around, so to speak, and bear the costs associated with that, or not bear the costs if they do not have the financial resources to do so, which means they then get lower quality healthcare. That is one point.

**Co-Chairman (Deputy Michael Moynihan):** I thank our witnesses, who have given details of their dedicated and lived experience, put it all to us and challenged us in a major way. I thank members of the joint committee on finance and our committee for being here and asking questions.

The next meeting of the Joint Committee on Disability Matters will be at 9 a.m. on Thursday, 24 March. The committee will have a photocall at 2 p.m. on the plinth of Leinster House prior to the launch of our report, Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities. I again thank the witnesses. I ask them to keep in touch with us. If they believe there is anything more they can advance or help us with, they

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should please feel free to contact us. We are only as strong as the voice we give to the evidence they have given us today. I again thank them very much. Our sincere thanks also to the team here for their hard work and dedication.

**Ms Nicola Meacle:** I thank the committee for letting us say our piece.

The joint committee adjourned at 11.51 a.m. until 9 a.m. on Thursday, 24 March 2022.