# Disability Power Ireland (DPI) Policy Submission to the Joint Oireachtas Committee On Disability Matters.

Re: Request for submission on The Rights-Based Approach and Disability Legislation

## Introduction

## Who are Disability Power Ireland?

Disability Power Ireland (DPI) is a grassroots Disabled Persons' Organisation (DPO) run entirely by and for disabled people. Our main goal is to celebrate the disabled community through annual events in Disability Pride Month in July, including our Pride and Power Festival and upcoming parade.

DPI bases its operations on the social model of disability, which maintains that on top of the limitations caused by a person's impairment, disabled people are additionally hindered by disabling societal barriers, such as inaccessible environments, lack of employment opportunities, lack of educational support and integration, lack of housing etc.

DPI believes that there is nothing wrong with being disabled and that social attitudes and barriers in The Republic of Ireland must change in order to provide a more inclusive society. We wish to advocate for and increase awareness of the issues which face the disabled community, such as high poverty levels, through our collaborations with groups including Disabled Artists and Disabled Academics (DADA), Disabled Women Ireland (DWI), Neuropride Ireland (NPI), Full Spectrum Ireland (FSI) and Clare Leader Form (CLF).

## **Disability Power Ireland – Policy Positions**

The overarching policy position of DPI is that the UNCRPD needs to be meaningfully implemented in Ireland. As a very young DPO, DPI is still in the process of developing our detailed policy position documents in line with national and international statistics and research. DPI intends on publishing our policy position statement in 2024, giving us time to conduct an exhaustive review of available research and to incorporate Census 2022 Disability data which is due to be published in September 2023. For this reason, this submission draws heavily on secondary data sources.

DPI are grateful for the opportunity to submit to the JOC on Disability Matters, but due to the points above and limited timeframe for this submission we have limited our scope to discussion of points two and four from the request from the JOC, which are:

- "The Disability Act 2005 must be updated in line with the UNCRPD", which is inclusive of the discussion:
- "The rights of people with disabilities need to move beyond anti-discrimination legislation to align with the UNCRPD and ensure appropriate economic and social supports to achieve equal access, participation, and outcomes in all areas

of service provision and employment, including independent needs assessment, services, advocacy, and redress."

#### **Definitions:**

#### 1. Disability:

The Disability Act (2005) refers to disability as:

"'disability', in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment" <sup>1</sup>

DPI believes this definition of disability is outdated, and advocate for a reform of the definition to take it away from it's medical models lens and bring it in line with the human rights lens found in the preamble to the UNCRPD:

"Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"<sup>2</sup>

#### 2. Discrimination.

The Disability Act does not define what discrimination against disabled people means. The UNCRPD provides a definition which should be incorporated into any new legislation relating to disability rights in Ireland, or any amendments to extant acts:

"'Discrimination on the basis of disability' means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation"

<sup>&</sup>lt;sup>1</sup> Disability Act (2005), 2 (1).

<sup>&</sup>lt;sup>2</sup> UNCRPD (2006), Preamble paragraph 5. Preamble | United Nations Enable

<sup>&</sup>lt;sup>3</sup> UNCRPD (2006), Article 2. Definitions. Article 2 – Definitions | United Nations Enable

## "The Disability Act 2005 must be updated in line with the UNCRPD"

The UNCRPD (2006)<sup>4</sup> is the highest piece of legislation pertaining to disability rights. Ireland ratified the UNCRPD in 2018 but never signed the Optional Protocol. DPI submitted that any amendments to existing disability legislation in the Republic of Ireland must be rooted in the rights-based approach to disability adopted by the UNCRPD. The Department Of Health has committed to trying to ensure that disabled people are enabled to integrate fully socially and economically.<sup>5</sup> For this ambition to be successfully realised the rights guaranteed to disabled people under the UNCRPD must be placed front and centre. The Disability Act (2005)<sup>6</sup> views disability policy through an anti-discrimination lens, but not strictly a rights-based lens. It limits its remit to access to public buildings, and partial access to healthcare and education and only employment in the public service.<sup>7</sup>

Whilst DPI believes the Disability Act 2005 is not fit for purpose and would welcome reform of the Act, we mirror the opinion expressed by stakeholders and public consultation<sup>8</sup> that disability policy in Ireland is "policy rich but implementation poor". DPI welcomes the Government proposal to develop a UNCRPD Implementation Plan for Ireland and firmly believe that the development of this plan, in collaboration with disabled people, should be the highest priority for disability policy-makers and the Joint Oireachtas Committee on Disability Matters. Therefore, we are focusing this submission around considerations for developing this plan.

This submission is structured around 7 key Articles from the UNCRPD (9, 19, 24, 27, 28, 30, and 31/33), providing a brief summary of each article, key national data in support of the article, and providing DPI commentary and recommendations.

# Selected UNCRPD Articles with DPI Commentary and Recommendations

# **Article 9 - Accessibility**

**Article Summary:** People with disabilities have the right to participate fully in all aspects of life through equal access to the physical environment, transportation, information and communications, and other public facilities and services in both rural and urban settings.

<sup>&</sup>lt;sup>4</sup> United Nations Convention On the Rights Of Persons With Disabilities (UNCRPD) <u>Convention on the Rights of Persons with Disabilities – Articles | United Nations Enable</u>

<sup>&</sup>lt;sup>5</sup> Department of Health (2021). *Disability Capacity Review to 2032: A Review of Social Care Demand and Capacity Requirements up to 2032* p. 17

<sup>&</sup>lt;sup>6</sup> Disability Act 2005 (irishstatutebook.ie)

<sup>&</sup>lt;sup>7</sup> Disability Act (2005) Preamble.

<sup>&</sup>lt;sup>8</sup> Ireland's Draft State Report under the United Nations Convention on the Rights of Persons with Disabilities - Report from Public and Stakeholder (CES, 2021)

General Comment, No. 2 of the UNCRPD which is based on Article 9 of the UNCRPD states:

"Accessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society. Without access to the physical environment, to transportation, to information and communication, including information and communications technologies and systems, and to other facilities and services open or provided to the public, persons with disabilities would not have equal opportunities for participation in their respective societies" <sup>9</sup>

### **DPI Commentary and Recommendations:**

Ireland does not currently have any legislation in place that addresses accessibility broadly across all sectors, and the Disability Act fails to consider the broadest meaning of accessibility.

An important consideration for Ireland is the European Accessibility Act (EAA), which will come into force in June of 2025. Ireland doesn't currently have any domestic legislation that comfortably aligns with the provisions of this act.

The European Accessibility Act (EAA) is an important part of EU disability law which provides the right to access essential products and services for disabled people, including:

#### **Products:**

- computers and operating systems;
- payment terminals and certain self-service terminals such as ATMs, ticketing and check-in machines, interactive self-service information terminals;
- smartphones and other equipment for accessing telecommunication services:
- TV equipment involving digital television services;
- e-readers.

#### Services:

- telephony services;
- services to access audiovisual media services;
- certain elements of air, bus, rail and water transport services such as websites, mobile services, electronic tickets, information;
- consumer banking;
- e-books;
- e-commerce;
- answer to emergency calls to the single European number '112'.<sup>10</sup>

As Article 9, Accessibility, is a particularly cross-cutting issue for people with disabilities across all aspects of life (and a key concern across other articles of the UNCRPD), we suggest that a National Accessibility Strategy is developed as a priority alongside the UNCRPD

<sup>&</sup>lt;sup>9</sup> Committee For The UNCRPD, General Comment, No. 2, 1.1. <u>CRPD/C/GC/2 (undocs.org)</u>

<sup>&</sup>lt;sup>10</sup> European Accessibility Act (EAA) Summary <u>EUR-Lex - 4403933 - EN - EUR-Lex (europa.eu)</u>

Implementation Plan. DPI recommends these correspond with the European Accessibility Act (EAA).

Implementation of Article 9 involves both the *identification* of and *elimination* of obstacles/barriers to access for disabled people in all aspects of life. Full identification of the scope of access needs requires stakeholder consultation and gathering of rich *qualitative* data from people with disabilities.

A National Accessibility Strategy would need to be developed from a **Whole-of-Government** perspective and involve specific targets across various sectors, including housing, climate action planning, transport and other aspects of service improvement and societal design. The principles of Universal Design also need to be embedded in designing the physical environment, products and services.

# Article 19: Living independently and being included in the community

**Article Summary:** People with disabilities have the right to live independently and be included in their communities

**DPI Commentary:** The European Network On Independent Living (ENIL) defines independent living as the daily demonstration of rights-based policies towards disabled people that enable them to live fully inclusive and independent lives. <sup>11</sup> The right for disabled people to live independently, which is to say have choice and control over our lives is enshrined in article 19 of the UNCRPD. Article 19 states that support services such as personal assistance should be made available for disabled people so that they are enabled to live independently and be integrated into the wider community and avoid segregation. <sup>12</sup> Ireland is falling in its obligation to support independent living. In 2017, the average time per day for personal assistance availability for disabled people was just 42 minutes. <sup>13</sup> Ireland does not have a standardised personal assistance service, something which the DPO Independent Living Movement Ireland (ILMI) have been calling for. <sup>14</sup> Moreover, a 2021 report from the Ombudsman <sup>15</sup> makes it clear that young disabled people are still liable to be locked in nursing homes for the elderly thus denying them a right to choose where and who they wish to live with as stipulated under article 19 of the UNCRPD.

**DPI Recommendation**: DPI recommends the full implementation of personal assistance in the Republic Of Ireland, through ILMI's personal assistance service (PAS) policy, the deinstitutionalization of disabled people and ring-fencing of HSE funds to provide for personal assistance.

<sup>&</sup>lt;sup>11</sup> European Network On Independent Living (ENIL) Independent Living - ENIL

<sup>&</sup>lt;sup>12</sup> UNCRPD, Article 19.B <u>Article 19 – Living independently and being included in the community | United Nations Enable</u>

<sup>&</sup>lt;sup>13</sup> Personal Assistance Service - Dáil Motion <u>Personal Assistance Service: Motion – Dáil Éireann (32nd Dáil) – Tuesday, 19 Nov 2019 – Houses of the Oireachtas</u>

<sup>&</sup>lt;sup>14</sup> ILMI (2022), *Pathway To A Personal Assistance Service (PAS)* Pathways-to-PAS-March-2022.pdf (ilmi.ie)

<sup>&</sup>lt;sup>15</sup> Ombudsman (2021), Wasted Lives. Wasted Lives | The Office Of The Ombudsman

### **Article 24 - Education**

**Article Summary:** People with disabilities have the right to education in inclusive and accessible environments on an equal basis with others, to enable them to meet their fullest potential.

**DPI commentary:** The Irish Human Rights And Equality Commission (IHREC) have raised concerns relating to the Education Of Persons With Special Educational Needs (EPSEN) Act (2004).<sup>16</sup> Amongst its recommended reforms IHREC suggests updating the EPSEN act in line with the Irish Human Rights Act (2014) while also bringing it into line with the UNCRPD which under article 24 mandates that states must provide for inclusive education.<sup>17</sup>

**DPI Recommendation:** Reform the EPSEN Act to bring it in line with Article 24 of the UNCRPD, to ensure that disabled children are granted a right to general education and that provisions for special classrooms or segregated learning rooms within mainstream schools are prioritised over segregated special schools which further exclude disabled children from society.

## **Article 27 – Work and Employment**

**Article Summary:** People with disabilities have the right to work in an environment that is open, inclusive and accessible and should be free from discrimination on the basis of disability throughout recruitment, employment and career advancement practices

#### **DPI Commentary and Recommendations:**

The European Commission Country Report for Ireland published in 2022 states that The Republic Of Ireland has a higher than average unemployment gap for disabled people at 38.6% and further notes that in 2019 less than a third of disabled people in Ireland were employed. Ireland has one of the lowest employment rates within the European Union (EU) standing at 26.2%, compared to the EU average of 48.1% in 2017.<sup>18</sup>

We posit five broad categories to consider regarding disabled people and (un)employment:

- 1. **People who are unable to work at all due to their disabilities.** The issues for this population, such as inadequate social protection supports and their risk of poverty are considered under Article 28, below.
- 2. Reasonable accommodations, supports and anti-discrimination measures for people with disabilities across all stages of employment (recruitment/interview practices, the work environment, and career progression). There is evidence of good practice in some larger organisations, the public sector, and organisations with a history of employing people with disabilities. However, The Government must do more to:

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<sup>&</sup>lt;sup>16</sup> IHREC (2023), Submission To The Review Of the Education Of Persons With Special Educational Needs ('EPSEN') Act (2004) Submission-on-the-Review-of-the-Education-for-Persons-with-Special-Educational-Needs-'EPSEN'-Act-2004.docx (live.com)

<sup>&</sup>lt;sup>17</sup> UNCRPD, Article 24. 2.(a): Education. <u>Article 24 – Education | United Nations Enable</u>

<sup>&</sup>lt;sup>18</sup> Employment and Disability | Social Justice Ireland

- Increase investment in employment support programmes, such as AHEAD's Willing Able Mentoring (WAM) Programme
- Ringfence funding for, and expand the Reasonable Accommodation Fund for accessible tools and technology in the workplace
- Educate employers about grants and schemes available under the Reasonable Accommodation Fund
- Educate employers on the social model of disability, to reduce stigma and misinformation about disability
- Highlight the work-force benefits or 'business case' of hiring people with disabilities (improved productivity, decision-making, innovation, and revenue)<sup>19</sup>
- Look at best practice examples from across the EU to see how disabled people can be included fully and inclusively in the labour market.

Lack of career progression has been highlighted by some employed people with disabilities<sup>17</sup> More research on the breadth of this problem and the reasons behind it is needed in order to propose solutions, e.g. if this is an employer attitudes/stigma concern or if targeted free training/upskilling courses are needed for people with disabilities to advance further in their chosen careers.

- 3. Barriers to employment for disabled people outside of workplace/employer considerations e.g. accessible transport, buildings and public spaces (see Article 9)
- 4. The cost-benefit for unemployed disabled people to take on work e.g. possible loss of disability allowance and medical card. This issue was considered in the 'Make work pay' strategic priority of the Comprehensive Employment Strategy for People with Disabilities 2015-2024, but not enough progress has been made<sup>20</sup>

We commend the expansion of free travel for 5 years after losing eligibility for Disability Allowance, but hold that this should be a lifetime entitlement for disabled people to cover the aforementioned additional cost of disability. Considered reform of Disability Allowance is needed from a two-pronged approach: Firstly, as it relates to employment/additional income, in particular for individuals with unpredictable self-employment income or working in the arts (see Article 30). Secondly, the suitability of baseline Disability Allowance as a sole, liveable income for people who are unable to work due to their disabilities (see Article 28).

The Medical Card should only be means-tested for people without long-term illnesses or disabilities. For people with disabilities and long-term illnesses, Medical Cards should be granted independent of income.

The cost of living with a disability, which ranges between €8,525 - €16,284 per year<sup>21</sup> does

<sup>&</sup>lt;sup>19</sup> Boston Consulting Group (2018). How Diverse Leadership Teams Boost Innovation.

<sup>&</sup>lt;sup>20</sup> Centre for Effective Services (2021) Ireland's Draft State Report under the UNCRPD - Report from Public and Stakeholder Consultations

<sup>&</sup>lt;sup>21</sup> Department of Social Protection (2021) The Cost of Disability in Ireland - Research Report

not change depending on the income of disabled people, so any targeted supports from the Government to absorb these costs should not be dependent on means.

5. Other barriers to employment for people with disabilities who are willing and able to take up work in the right conditions. This is particularly relevant for individuals with chronic illnesses, psychosocial conditions, 'dynamic' disabilities<sup>22</sup> and other "invisible" disabilities. Flexible working hours and work from home options are a significant need for this population, where ability to travel and/or work may fluctuate drastically from day to day.

Research has shown substantial demand for employment among working-age people with a disability who are not working at present, an estimated 37% of working-age people with disabilities would work 'if the circumstances were right'<sup>23</sup>. We posit that this is a significant number of people not being captured by current research into employment barriers, nor Government efforts to make employment accessible. Further research, in particular *qualitative* research and consultation, is mandatory for the State to capture the true, varied, lived experience of (un)employment from people with disabilities in Ireland and thus be in the position to design targeted policies and programmes to address them. In particular, there is a lack of data and understanding surrounding dynamic disabilities.

## Article 28 – Adequate standard of living and social protection

**Article Summary:** People with disabilities have the right to an adequate standard of living, including adequate food, clothing, housing, and effective social protection programmes

### **DPI Commentary and Recommendations:**

People with disabilities who are unable to work have the highest risk of poverty in Ireland<sup>24</sup>. CSO SILC data shows that two in five people not working due to disability are at risk of poverty, while one in five live in consistent poverty<sup>25</sup>. In 2021 poverty rates increased significantly for people with disabilities despite reduction in the national average rates of poverty<sup>26</sup>. This highlights a need for targeted poverty reduction programmes and policies for people with disabilities.

### **Disability Allowance Rates**

Ireland spends a lower percentage of social protection on disability supports than the EU average<sup>27</sup>. Both the Covid-19 pandemic and cost-of-living crisis have brought into sharp focus the insufficiency of core welfare provisions in Ireland. The current personal rate of Disability Allowance is €220 per week, whereas people unable to work during the pandemic were awarded €350 per week. This demonstrates acknowledgement that €220 is not a sufficient

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<sup>&</sup>lt;sup>22</sup> "Dynamic disability is a relatively new concept that means that a disability oscillates in severity (normally tied to what is called a "flare"), where all or one of the symptoms of a chronic illness are more active or worsen for a period of time" (disartnow.org)

<sup>&</sup>lt;sup>23</sup> Watson and Nolan (2011) A Social Portrait of People with Disabilities in Ireland

<sup>&</sup>lt;sup>24</sup> Socialjustice.ie (2022) Poverty Focus

<sup>&</sup>lt;sup>25</sup> CSO. Survey on Income and Living Conditions 2021

<sup>&</sup>lt;sup>26</sup> Disability Federation of Ireland (2022) Pre Budget Submission 2023

<sup>&</sup>lt;sup>27</sup> EuroStat 2018

basic income. The 'Basic Income for the Arts BIA' Pilot Programme, which DPI welcomes, with a weekly rate of €325 per week, also reflects what research has presumably demonstrated to be a livable wage. Previous increases in the rates of Disability Allowance aren't in-line with inflation at minimum<sup>23</sup>.

**Recommendation:** Thorough research and economic forecasting is needed for this complicated issue, but DPI posit that if the UNCRPD were meaningfully implemented across all articles, then barriers would be reduced for the 37% of disabled people who wish to be in work<sup>20</sup>, which along with improved access of people with disabilities participating in wider society and cultural activities, would lead to long-term net economic gain which could offset the increased cost of the State providing a liveable disability allowance for those unable to work.

#### **Disability Allowance Process**

Disability Allowance has a high rate of refusal<sup>28</sup> and a high rate of successful appeals (63% allowed, partly allowed or revised in 2020<sup>29</sup>). DPI commend JOC members for raising this concern in the Oireachtas<sup>26</sup> and side with other disability non-profits who have expressed concern and called for further investigation<sup>25</sup>.

In the experience of DPI members, there is vast anecdotal experience and advice from people with disabilities *and our medical providers* that disability allowance applications won't be accepted the first time and need to be appealed as standard. The Minister of Social Protection's statement that 'it is important to highlight the value of providing all relevant information at the initial application stage'<sup>26</sup> doesn't ring-true for those of us who have been forewarned by other disabled people and/or our medical practitioners to include extensive details and medical reports, yet still had to go through the lengthy appeals process.

**Recommendation:** A full investigation into the Disability Allowance process is needed and should consider the qualifications and experience of who makes the initial decision versus who is consulted for appeal of Disability Allowance decisions.

#### Housing

In 2016, an estimated 27% of homeless people had a disability, which was double the rate of the general population<sup>30</sup> Overall, it is vital that disabled people, their rights and access needs are considered at every step of Government response to the housing crisis.

**Recommendation:** The Department of Housing, Local Government and Heritage's attention is brought to the publicpolicy.ie review of housing policy for disabled people<sup>31</sup> and 'disability-proof' all housing policy and programmes through literature review and consultation with disabled people and disability organisations.

<sup>&</sup>lt;sup>28</sup> The Irish Examiner (13 Feb, 2022). <u>More people were refused Disability Allowance than number granted the payment</u>

<sup>&</sup>lt;sup>29</sup> Social Welfare Appeals - Dáil Éireann Debate, Wednesday - 24 March 2021

<sup>&</sup>lt;sup>30</sup> CSO Census 2016

<sup>&</sup>lt;sup>31</sup> Leonard, E (2022). Reviewing Disabled Housing Policies in Ireland: Are These Policies Fit for Purpose?

# Article 30 – Participation in cultural life, recreation, leisure and sport

**Article Summary:** People with disabilities have the right to partake in cultural life on an equal basis with others, including access to cultural activities and materials, performances and services, and recreational, leisure and sporting activities

**DPI Commentary and Recommendations:** Disabled artists face precarious employment, something that all artists struggle with, but this is confounded by the fact that many disabled artists face the prospects of having their social welfare stripped from them or reduced, if they try to earn money from artistic projects, as there is no system tied to the Department Of Social Protection to deal with inconsistent arts payments.<sup>32</sup> Disabled artists and facilitators, including DPI's own committee members, are unable to apply for festival funding, community or individual grants, bursaries, or financial awards, for fear of losing their basic allowances and their medical card.

Barriers to access for the arts include not only the financial ones above, but also come down to lack of access to building infrastructure, sign language or lack of Personal Assistance hours to enable disabled people to attend or access events.

#### Recommendations:

- To add a provision in social protection legislation to exclude income from grants, bursaries, and awards from means assessment. This is similar to the income disregard in "Catherine's Law," which allows disabled academics to keep their PhD scholarships without losing their supports, including disability allowance, medical card and free travel pass.
- To legislate for the right to personal assistance hours and drastically increase personal assistance hours to enable disabled audiences to access and participate in the arts. (see Article 19 above)
- 3. To ensure that all grants offered to disabled and non-disabled artists do not assess earnings as income, to allow for disabled people to retain their basic supports such as disability allowance which cover only the additional cost of having a disability<sup>33</sup>.

# Article 31 - Statistics and data collection, and Article 33 - National implementation and monitoring

Article Summaries: Countries must collect statistical and research data about people with

<sup>&</sup>lt;sup>32</sup> Conway, E. (2022). <u>Safe and respectful working envt (oireachtas.ie)</u>

<sup>&</sup>lt;sup>33</sup> The additional annual cost of living with a disability, as demonstrated in the The INDECOn Cost of Disability Report, is between 8,700-12,300 euro. This is roughly the payment of Blind Pension or Disability Allowance at 208 euro a week, yet instead of going towards covering the additional cost of disability, it is assumed that this is enough for a disabled person to live on and pay rent on.

disabilities, with the active involvement of people with disabilities, to assess need and inform implementation of the UNCRPD (Article 31), and Countries must establish or strengthen frameworks to monitor implementation of the UNCRPD (Article 33).

Article 31 "requires inclusion of persons with disabilities in collection, analysis and dissemination of data, for example, regarding *choosing the criteria used in gathering the data or helping to work out how to include the broadest possible range of persons with disabilities in surveys,* including those who may be the most marginalised."<sup>34</sup> [emphasis added]

#### **DPI Commentary and Recommendations:**

Article 31 represents a historical first in international human rights law: statistics and data collection included in a human rights treaty. This article differs from previous articles in that Article 31 is a tool in the promotion of rights, rather than a right in itself 35

DPI believes that Article 31 warrants consideration as a key cornerstone to inform all implementation planning for the UNCRPD and thus should not be overlooked. Researching a response to this submission has highlighted how dated and insufficient disability research in Ireland is, and how it fails to capture, for the most part, the nuanced and varied experience and needs from a group (people with disabilities) which is far from monolithic.

Where CSO Census, and further the National Disability Survey (2006) is useful to an extent, the most meaningful data DPI found to support this submission (i.e. that best represented the lived experience of our members) was from Ireland's "Draft State Report under the UNCRPD - Report from Public and Stakeholder Consultations" which provided *qualitative* feedback from 'advocacy organisations, people with disabilities, services and other government departments'. We can't ascertain how many individuals with disabilities were represented across participation, but we do know that this data is more meaningful regarding policy and programme design and implementation than other national statistics and that attendees 'reported feeling that their voices or representations were not taken on board during policy design' (p.3).

**Recommendation:** DPI acknowledge the practicalities and the resource/cost needs for consultations and qualitative data-collection, compared to survey/tick-box quantitative surveys, but we posit that even a *once-off* mass consultation and gathering of qualitative data, utilising DPOs and disability non-profits in Ireland, and centred around the articles of the UNCRPD, would provide invaluable qualitative experiences which can be used to inform a UNCRPD Implementation Plan and design of the accompanying monitoring/evaluation processes which can then be gathered through more traditional and feasible quantitative CSO data; once survey design has been informed by the real needs of people with disabilities.

<sup>&</sup>lt;sup>34</sup> Pedersen, M in Article 31 [Statistics and Data Collection] p.560-562 in the UNCRPD: A commentary (2018)

<sup>&</sup>lt;sup>35</sup> National Disability Authority (2020) <u>NDA Review Paper on UNCRPD Article 31: Statistic and data</u> collection

<sup>&</sup>lt;sup>36</sup> Centre for Effective Services (2021) Ireland's Draft State Report under the UNCRPD - Report from Public and Stakeholder Consultations

## **Proposed National Disability Survey, 2026**

As the NDA highlight<sup>30</sup>, Ireland is making progress in large-scale, quantitative capture (e.g., aligning Census questions with international standards for disability data). We support the NDA proposal/CSO discussions to run a second National Disability Survey following the Census 2026. However, it is absolutely vital, in our opinion, that further consultation with people with disabilities is conducted in the interim to inform the design of the next National Disability Survey. A 2026 NDS would mark *twenty years* since the last national attempt to capture meaningful, disaggregated disability data; therefore, it is absolutely vital that extensive collaboration with disabled people is conducted to inform the questions needed on this survey, otherwise we risk another several decades of meaningful disability data not being captured or considered in policy and programme design. Disaggregated data is needed, not only at the level of disability type/profiling, but crucially at the access needs across different disabilities. DPI particularly feel that psychosocial, dynamic and invisible disabilities are not considered or being adequately captured in the national data.

#### Compensating people with disabilities for their labour

Further, and relevant to Article 28, which considers the poverty profile of people with disabilities, DPI support the suggestion to financially compensate, without affecting disability allowance, disabled people who take part in Government consultations and feedback exercises.<sup>32</sup> Incentivising such practices may improve the quantity of participants who participate in such exercises.

### Article 33 - National implementation and monitoring

Article 33 is included in this section as it pertains to:

- The overall recommendation of DPI's submission to prioritise a UNCRPD Implementation Plan as the foremost priority for disability policy in Ireland
- DPI's position that data collection/needs assessment, implementation, monitoring and evaluation need to be key considerations underpinning all articles of the UNCRPD and it's implementation, and
- The need for people with disabilities to be included, as with data collection, in the design
  of monitoring and evaluation measures of a UNCRPD Implementation Plan to ensure
  that the desired outcomes of an implementation plan are being monitored and evaluated
  appropriately

# **Conclusion: Overarching Recommendations**

- The Disability Act (2005) is not fit for purpose and reform is welcome, but resources should be prioritised toward actionable disability planning in line with the UNCRPD
- A UNCRPD Implementation Plan must be the top priority for the disability policy landscape in Ireland.
- Second to a UNCRPD Implementation Plan, a National Accessibility Strategy would be a valuable starting point to improve overall disability legislation in Ireland, as accessibility underpins many of the issues and barriers facing people with disabilities in all aspects of life.

- Collaboration and consultation with disabled people and their organisations (DPOs) must be prioritised at every stage of policy and programme planning: from data collection and needs assessment to inform implementation planning, through to design and delivery of ongoing monitoring and evaluation measures
- Current data-collection methods (namely Census data) are not capturing the lived experiences and needs of people with disabilities. We are a far-from monolithic group and a broad range of voices and needs are being left behind currently, particularly for those with "invisible disabilities". The gathering of both qualitative and quantitative data is needed, with particular attention paid to the advertising and accessibility of consultation to ensure maximum representation
- DPI support the position of the NDA<sup>31</sup> to conduct a second National Disability Survey following the Census 2026, but we propose that extensive consultation with disabled people in the design of this survey is fundamental to the adequate capture of meaningful data
- The Government needs to invest and ring-fence significant funding and resources into the implementation of UNCRPD and ongoing data-collection and evaluation.
- Ireland needs to sign the Optional Protocol of the UNCRPD. This will demonstrate to DPI and disabled people nationally that the State is committed to realising our rights under the UNCRPD
- Disability rights aren't a niche, silo or secondary consideration but are relevant crosscutting policy issues. Therefore, in addition to a UNCRPD Implementation Plan, DPI calls for a Whole-of-Government approach to disability, where disabled people's rights, accessibility and inclusivity are considered in policy-making across housing, transportation, education, employment, culture and climate action. As standard practice, ALL new Governmental policy changes need to be reviewed from a disability/UNCRPD lens before they are implemented
- DPI welcomes the work done by the NDA in publishing a series of in-depth papers on various articles of the UNCRPD (ongoing)<sup>37</sup>, which cover the main data around specific articles and provide an overview of policies and programmes in the Irish context. However, as these papers average upward of 50-100 pages, DPI are concerned about the Government heeding this valuable research and referring to it when implementation planning. We recommend consultative work with suitably qualified disabled people to draw key conclusions from these papers, alongside the gathering of more relevant, upto-date, disaggregated, quantitative and qualitative data on the needs of disabled people.
- With concerted effort, Ireland has the opportunity to become a best-practice example for UNCRPD implementation, and by extension, disability rights as a whole, should the State meaningfully invest resources (time, people, funding) into its realisation

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<sup>&</sup>lt;sup>37</sup> National Disability Authority (2020-2022) <u>Series of Papers on Individual United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Articles</u>