**Disabled Women Ireland**

**Submission on the Draft Initial State Report under the Convention on the Rights of Persons with Disabilities**

**April 2021**

**Introduction**

## **Disabled Women Ireland**

Disabled Women Ireland (DWI) is the national Disabled People’s Organisation (DPO) representing disabled self-identified women, girls, non-binary and gender non-conforming people in Ireland. DWI, as a member of the DPO Coalition and the Disability Participation and Consultation Network, welcomes the opportunity to comment on Ireland’s Draft Initial State Report on the UN Convention of Persons with Disabilities (UNCRPD).

## **UN CRPD**

Ireland ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2018 after an almost 12 year wait. The State did not ratify the Optional Protocol to the CRPD (OP-CRPD), contrary to commitments made over the previous decade. Ireland also included declarations and reservations on three key articles of the CRPD - Articles 12, 14 and 27. We call for them to be removed.

The submission of Ireland’s first report to the CRPD Committee is an important part of the States obligations under the Convention and it is vital that the State provide as much information as possible on current laws, policies and practices which impact the lives of disabled people in this process.

## **Consultation Process and Report Structure**

In March we held three consultation meetings focusing on a number of themes including education, employment, health, family, access to justice and complaints mechanisms and independent living. In these meetings, participants were assigned to breakout rooms relating to these themes. In total eighteen breakout sessions were held. Forty-nine participants attended these events, with several participants attending more than one session.

Below we outline some of the main issues identified over the course of these consultations. The issues are listed under the main Article of the UNCRPD they relate to. We also highlight a number of other areas which we believe have been omitted from the Draft Initial State Report or issues which require further clarity.

## **Note on Language**

We are a Disabled Persons Organisation (DPO) and use identity first language ("disabled people") in most of our materials. However, throughout this submission we alternate between the person first language used in the Convention ("persons with disabilities") and identity first language in recognition of the multiple ways in which disabled people may choose to identify.

# **Recurring Issues**

This submission is structured by article. However, a number of recurrent issues were identified across the Draft Initial State Report; and we have chosen to highlight these here.

First, data disaggregated by gender, ethnicity and impairment(s) is broadly absent from the report. Where this data is available it should be included; where it does not exist, plans to gather this data should be clearly outlined.

Second, specific measures or policies to address the rights of persons with disabilities have not been sufficiently detailed in the report. This includes where the CRPD Committee specifically requests information on such measures. We have attempted to highlight these omissions in our comments on each specific article. Where measures are detailed in the Draft Initial State Report, information on the oversight and monitoring mechanisms for these policies are not included. We request that this is included in the State Report.

Finally, more information on the inclusion of disabled people and their representative organisations (DPOs) is required. There is insufficient information on the involvement of disabled people in the development, implementation, monitoring and evaluation of any of the measures outlined in the report.

# **Articles**

## **Articles 1-4**

The Draft Initial State Report outlines the multiple definitions of disability which exist under Irish legislation. The current definitions do not reflect our membership nor are they in accordance with the Convention on the Rights of Persons with Disabilities. This impacts not only on how disabled people are viewed within Irish society but it also impacts the accurate collection of data and statistics upon which services to disabled people are based. We call on the State to outline what action it plans to take to implement a rights-based definition consistent with the CRPD across all legislation.

In the final report to the CRPD Committee the State should clearly differentiate between DPOs and non-DPOs. The State should also outline how it plans to provide recognition, prioritisation and resources (including capacity building and funding) to DPOs in line with its obligations under Article 4(3) CRPD and General Comment No. 7.

## **Article 5 - Equality and non-discrimination**

Ireland has a number of legislative and policy measures with the stated aim of tackling discrimination and inequality.

Further information on the enforcement of the State’s equality and anti-discrimination frameworks is needed. Over the course of our consultations, it was raised that enforcement of non-discrimination legislation was an issue.

The definition of disability within the Acts must be laid out in the report. The consultations highlighted that many people felt that there was a reluctance to recognise, or misunderstanding of, disability as a human rights issue. We task the State with outlining it’s plans to introduce more training and education around disability and the human rights model of disability, in all areas of life.

While there is a clear framework for addressing discrimination based on specific grounds, the Draft Initial State Report does not detail efforts to address intersecting forms of discrimination. Our entire membership is comprised of people who have experinced discrimination on the basis of both gender and disability. Many of our members experince discrimination on other bases as well. We request that the State outline what measures it has in place, or will put in place, to address these compound inequalities. Furthermore, we request that the State outline how disabled people will be involved in the planning, oversight, enforcement and monitoring of these measures.

## Article 6 - Women and Girls

Disabled women face additional discrimination because of their gender. This was clear from our consultations and impacted on many participants. We call on the State to outline specific policies that it has or will have to address this, for example through affirmative-action programmes and collection of relevant disaggregated data.

We also call on the State to outline its policies in relation to increasing the number of disabled women at decision-making level in decision-making bodies.

We know that there are more disabled women than men. We request that the State includes data disaggregated on the basis of gender, ethnicity and disability in the State Report. Where this data doesn’t exist we call on the State to outline plans to improve data capture and disaggregation.

We have chosen to reference dual or multiple marginalisations throughout the report. No issue which impacts disabled people does not also impact disabled women and disabled people of other marginalised genders. No issue which impacts women or people of other marginalised genders, does not also impact disabled women or disabled or people of other marginalised genders. This approach is consistent with the Convention.

## **Article 7 - Children**

Over the course of our consultations, disabled girls and young non-binary people highlighted the limited availability of diagnostic services, early intervention supports and lack of support during key transitional stages including in transitioning from child to adult services. This is of particular relevance for disabled women and girls who are often diagnosed later or misdiagnosed with certain conditions and therefore face delays in accessing supports. We call on the State to detail in the State Report the processes it has in place to ensure children and young people can access diagnostic services and early intervention supports, the steps taken to address gender inequalities in accessing these services and supports and the measures in place, if any, to support children and young people during transitions. Where none are available, we request that the State outline plans to introduce such measures, and outline how it will involve disabled people in the development, implementation, monitoring and oversight of such measures.

Our consultations have highlighted that many young disabled people do not feel they are consulted on issues which affect them. The Draft Initial State report provides a detailed account of the strategies and guidance document which have been published on the participation of children and young people in decision-making. However, there is no information on the States implementation of such policies or how and when it has consulted with children and young people. The State should address this, as an obligation under Article 4(3) and Article 7 CRPD, in their report to the CRPD Committee.

Further we call on the State to provide information on the legislative provisions and any additional measures in place which allow or limit the participation of children and young people with disabilities in decisions which affect them, for example decisions regarding medical treatment, both physical and mental health, and education. Access to disability- and age-appropriate supports should also be addressed here.

## **Article 8 - Awareness raising**

The initial report makes reference to strategies and public campaigns to raise awareness of persons with disabilities. First, the Draft Initial State Report does not provide information on whether or not such campaigns are communicated via multiple accessible forms such as Irish Sign Language (ISL) and Easy to Read.

The State references a number of initiatives, including The Green Ribbon Mental Health Campaign. We request that more information be provided on the active participation of disabled people and their representative organisations in such campaigns.

We also request further information on the participation of persons with disabilities and their representative organisations (DPOs) in the development, implementation, monitoring and evaluation of these strategies and campaigns be provided.

We call for greater clarity on measures striving to combat stigmas, stereotypes and harmful attitudes towards persons with disabilities. This also includes information on anti-bullying.

The Draft Initial State Report also fails to mention or identify any approach to ensure that media portrayals of persons with disabilities are in line with a human rights based approach to people with disabilities. We call on the State to outline what measures it has in place, or in the absence of such measures, what measures will be developed, and how disabled people will be involved.

## **Article 9 - Accessibility**

We call on the State to provide more data on the funding available to make public services and buildings accessible to disabled people. We also request details on training provided to staff on how to make buildings, systems and approaches accessible and free from discrimination.

We request that the State include information on what resources, guides and guidelines are used by the State to ensure public information is accessible. We call on the State to include details of what strategies and policies are in place to ensure information is accessible in a multitude of formats and how this implementation is monitored.

We ask that the State outline details of resources which have been put in place to support disabled people’s participation and communication needs, both in terms of access to assistive technology and aides, including Augmentative and Assistive Communication technology.

We request that details of measures used by the State in ensuring they themselves are accessible and fully support disabled people’s participation are included in the State Report.

Information about these supports and structures is a crucial part of accessibility. Information initiatives such as Assist Ireland have ceased operations due to funding. Information on the specific plans and resources the state intends to put in place to replace them should be included in the State Report.

Our consultations highlighted the fact the current system requires that a person be in employment or education in order to access assistive technology such as screen readers. This creates barriers to disabled people who require such supports. We call on the state to outline measures to address this.

We call on the State to address how disabled people are involved in the oversight and monitoring of these systems.

The State should include information policies and guidelines on making services and buildings in the private sector accessible to people with disabilities.

From our consultations, it emerged that access to public services and transport is much poorer in rural areas. We request that the State provide data on the accessibility of rural transport networks and the scope of this accessibility.

## **Article 10 – Right to life**

The Dying with Dignity Bill 2020 is currently under debate in the Irish Legislature. We insist that the State outline how structures will ensure that the rights of disabled people are upheld under any new system. We request that the State outline plans to include disabled people and their representative organisations in this process.

The Draft Initial State Report references the ‘Ethical framework for decision-making in a pandemic’ document. Further examination of this document is required under this heading, including the steps taken to ensure that the equal right to life of disabled people is thoroughly embedded in practice, and that the use of ‘quality of life’ assessments in medical practice do not undermine this right.

## **Article 11 – Situations of risk and humanitarian emergencies**

In our consultations, situations of risk and humanitarian emergencies were mainly discussed in the context of COVID-19. It was broadly felt that the State’s response to the pandemic had significantly added to difficulties already faced by disabled people, particularly for disabled women. It has also created new difficulties for a number of people.

One issue not raised by the Draft Initial State Report was access to disability services and supports, other than education. Our members noted that access to PA support, transport, auxiliary treatment and home help was limited over the course of the pandemic. Particular concern was raised for persons in nursing homes and other residential and congregated settings. We call on the state to examine the impact of the Covid 19 response on the rights of disabled people.

An area of concern was the treatment of disabled people in access to health care over the course of the pandemic. The lack of data disaggregated on the basis of disability was also raised as an issue, with people expressing concern that the full picture of death and poor medical outcomes of people with disabilities is unclear. With the UK reporting that approximately two thirds of their deaths attributable to Covid-19 were those of disabled people, it is essential that this information is gathered and made available in Ireland to inform best practice in the future. We request that the State outlines how it plans to collect this data moving forward. We also request that the State provide details on how this data will be disaggregated on the basis of gender, ethnicity and impairment type(s).

We also request more information on measures put in place to ensure that disabled people were able to access support and advocacy in hospital and institutional settings over the course of the pandemic.

One issue that was raised consistently across the consultations was the position of disabled people after the pandemic. Many people raised that as a result of the pandemic they had been granted access requirements previously denied to them including remote work, remote education, telemedicine and more online events. There was a general concern that as we enter the stage of pandemic recovery, these gains for access would be lost. It is the State’s obligation to ensure that we “build back better” following a disaster, we therefore request that the State outlines all measures which will be taken to ensure that disabled people and their full rights are included in this process.

## **Article 12 – Equal recognition before the law**

Disabled Women Ireland calls for the State to remove the reservations and declarations of understanding pertaining to Article 12 and 14. These reservations are contrary to the general principles of UN CRPD. Substituted decision-making violates the dignity and autonomy of disabled people. The State must recognise the full personhood of all disabled people, we insist that the State Report outline how it plans to remove these declarations.

Legal capacity is a particularly gendered issue. Women and non-binary people are more likely to experience subsistuted decision-making. We therefore request that all reforms are gender-proofed, and are in line with Article 12.

Over the course of our consultations, many people have expressed trauma and elevated vulnerability to abuse as a result of substituted decision-making, in particular in healthcare settings.

Alongside the trauma of formal substituted decision-making, issues were raised about the prevailing attitude amongst professionals that they could override disabled people's decisions. This prevailing paternalistic attitude will continue as long as the State resists recognising the full atonomy of disabled people. The State should outline its plans to make clear that disabled persons choices are fully theirs to make.

## **Article 13 – Access to justice**

Participants in DWI’s consultations referenced the inaccessibility of complaints mechanisms from an organisational level up to and including the courts system on a number of occasions. They also referred to the lack of accessible information or disability awareness among many of complaints mechanisms. Women, girls and non-binary or genderqueer disabled people are more likely to have to resort to the courts to implement their rights or access justice as victims to a crime. Therefore, we call on the State Report to outline what measures they have put in place to ensure the accessibility of information and complaints mechanisms to all persons with disabilities and the required level of awareness of and sensitivity to disabled people’s experiences in these systems. The State should also include information on any measures in place to raise awareness among persons with disabilities, including those living in institutional settings, of their options to access justice and redress.

In the final report, the State should outline the measures they have or intend to put in place regarding access to independent advocacy and legal representation for persons with disabilities who wish to lodge a complaint, who are involved in a legal case or who wish to challenge their detainment, as well as what steps the State and its bodies intend to take to ensure that disabled people, in particular disabled women and other gender minority people, are not unfairly discriminated against throughout its activities such as in assessment of parental capacity processes carried out by, or at the request of, State bodies.

Finally, we call on State to outline when it intends to ratify the Optional Protocol to the Convention to ensure disabled women, non-binary and genderqueer people in Ireland can access complaints mechanisms on an international level.

## **Article 14 – Liberty and security of person**

The information in the State report on use of seclusion and restraint is at odds with the lived experience of our members. We are particularly concerned about protection measures which codify the use of restrictive practices rather than abolish them.

We insist that the State include more data about the situation of women with disabilities in prison and in forensic psychiatric settings, disaggregated on the basis of gender, ethnicity and impairment type(s).

## **Article 15 – Freedom of torture or cruel, inhuman or degrading treatment**

We call on the State to outline its position on the use of restraint and seclusion and other aversive practices in all healthcare, educational and institutional settings, and to detail the monitoring of their use and any regulatory measures in place to ensure that these practices are in full compliance with the UN CRPD and do not constitute discriminatory and degrading treatment of people with disabilities.

## **Article 16 – Freedom from exploitation, violence and abuse**

#### Disability Hate Crime/Hate Speech

Disability hate crime is different from other forms of hate crime because it is often carried out by people who are known to us in the form of family members and “carers”. Disability hate crime has not been adequately legislated for in other jurisdictions because disability has been added to the list of groups at particular risk of hate crime without adequately taking into account the specific nature of disability hate crime.

We ask that the State include information on how it plans to legislate for Disability Hate Crime and Disability Hate Speech,

#### Domestic, sexual and gender-based violence

Disabled women are at higher risk of domestic, sexual and gender-based violence than our non-disabled peers. We are also at higher risk of abuse from other family members and carers. We ask that the State outlines measures to resource domestic, sexual and gender-based violence services to adequately support disabled people. The State is obliged to ensure that definitions of abuse and gender-based violence are properly expanded to cover the complex forms of abuse experienced by disabled women - this includes violence from carers and support workers, in institutional or residential settings, and from a broad range of family members. Alongside this, specific forms of abuse such as the removal of medication, mobility aids and other supports, must be addressed by the State.

While we address poverty under Article 28, we must acknowledge the way in which it contributes to the vulnerability of disabled people to violence. Disabled women are often financially dependent on family members which increases their risk of abuse. Research has shown that means testing of Disability Allowance and other disability-related supports, in particular where the earnings of a spouse, civil partner or cohabitant may reduce the disabled person’s allowance, and therefore reduce their financial independence, is a contributing factor to the significantly higher rates of coercion, violence and abuse experienced by disabled people[[1]](#footnote-0). This was also reflected in testimonies provided during our consultations. We call on the State to address systems which render disabled people more vulnerable to abuse.

## **Article 17 – Protecting the integrity of the person**

The State should provide more detail into where ECT is performed under the direction of two consultants without the consent of the person receiving the treatment. There are no facilities or practitioners qualified to perform psychosurgery in Ireland at present but, as set out in the Draft Initial State Report, it can be performed without consent. We would like the State to outline plans to remove these provisions.

We call on the State to outline the specific domestic measures which ensure that abortion, contraception and sterilisation are not forced upon disabled women, trans men or non-binary people without their consent.

## **Article 18 – Liberty of movement and nationality**

Our membership has identified Brexit as a situation which is imposing limitations on the freedom of movement of disabled people. The current arrangements infringe on the liberty of movement of guide and assistance dog owners in particular, as they face restrictions when bringing their dog to the UK. We call on the State to include these issues in the State Report and to outline its plans for addressing these substantial barriers.

The Draft Initial State Report states that persons with disabilities have the same right to nationality and right of movement as the rest of society. The Draft Initial State Report has omitted the constraints placed on persons with disabilities as both a result of the pandemic and as an unseen consequence of Brexit. The State must outline equality assessments it has undertaken on this issue, or its future plans to do so.

Disabled members of the Traveller community and other ethnic minority nomadic cultures have reported difficulty in accessing disability services and supports without the requirement for a fixed address. Moreover, they experience difficulty in being supported to participate fully in the cultural life of their communities, including their right to travel, with the majority of halting sites and other Traveller-specific accommodation being inaccessible. We call upon the State to outline the measures that it will put in place to ensure that nomadic people’s right to movement and equal cultural participation is fully recognised and vindicated. We also call upon the State to include details on how disabled people, particularly those from traditionally nomadic communities, will be involved in the development, implementation, oversight and monitoring of any such measures.

We also call on the State to provide details of policies and guidelines in place to ensure the equal treatment of persons with disabilities in relation to migration and asylum, and details of how it engages disabled people in respect to these issues. We also call for gender, ethnicity and impairment type disaggregated data to be provided, in relation to migration and asylum. Where this data is not available, we request that the State outline plans to ensure its collection.

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

The Draft Initial State Report references challenges in the implementation of Time on to Move on, but does not provide details on how it plans to address these challenges. We call on the State to provide gender, ethnicity and disability disaggregated data on the number of disabled people moved into the community, compared to those moving on to other care settings. We also call on the State to provide disaggregated data on those who continue to live in congregated settings. The State should outline the policies and guidelines in place to ensure that the agency of disabled people moving out of institutional settings is protected.

In our consultations, disabled women, particularly older disabled women, identified affordable, accessible and secure housing as an urgent need. The State should outline how its policies and guidelines will specifically address the needs of disabled women, of all ages and impairments, and how it will involve disabled women in the future development of these policies.

Disabled women of all ages with support needs require Personal Assistance Services (PAS) to be provided based on self-assessment and as a right. The Draft Initial State Report puts PAS in with primary medical care, demonstrating the systemic medical model approach to disabled people’s lives. The Draft Initial State Report also fails to mention that the current Personalised Budgets pilot excludes people without an existing service. We also call on the State to provide details in relation to the number of individuals requiring such support, disaggregated by gender, ethnicity and disability type.

Disabled women have identified the need for accessible transport as a significant determinant for where they live. A lack of accessible rural housing has restricted people’s choice of where they want to live. The State should outline what policies it has in place, or will put in place to address this issue. It is important that this outline provide an update on the introduction of the promised Transport Support Scheme, including a timeline for its implementation.

We call for greater inclusion of information relating to older disabled women under this Article.

The State should also provide information on how disabled people, particularly older people, children, gender and ethnic minority, LGBTQIA+ and otherwise additionally marginalised disabled people, are fully included in the policy-making structures outlined in this Article.

## Article 20 – Personal mobility

The Draft Initial State Report makes reference to securing access to all types of personal mobility aids used by people with disabilities and makes reference to guide dogs under this category. However, the report makes no mention of the use of assistance dogs or other support animals by disabled people. We ask the State to clarify whether it recognises the use of these animals as personal mobility aids and, if so, we call upon the State to outline what steps have been undertaken to resource and support their use.

We also call on the State to provide more detail on measures to encourage the research, development and production of accessibility aids and other forms of assistive technology for persons with disabilities and ask for specific detail on measures to ensure that people with disabilities, including disabled children, have access to on-training mobility skills.

## **Article 21 – Freedom of expression and opinion, and access to information**

## It is clear from our consultations that the provision of information in accessible formats by public bodies is not practiced by all public bodies. We call on the State to address provision for electronic correspondence in a manner which respects the privacy rights of all disabled people.

It was also highlighted by our consultation participants that often the method of information provision from healthcare providers and State bodies is inaccessible, with a structural lack of understanding of different communication needs caused by language-processing issues, dyslexia or other conditions. We ask that the State include information on policies the State has in place to monitor and address these accessibility issues and to improve awareness of information accessibility among its staff and practitioners.We also ask the State to provide detail on the involvement of disabled people in the development and implementation of such policies.

Concerns were also raised regarding the level of involvement of religious and faith-based organisations in the provision of disability-related services. We request that the State include details of measures in place to monitor the provision of these services and to ensure that disabled people’s freedom of expression and opinion and their right to information, free from religious influence, is upheld in these organisations’ practices.

We call on the State to provide robust and transparent information on the involvement of faith-based organisations in the provision of healthcare, rehabilitative and other disability-related services and to highlight any cases whereby access to information or supports may be influenced by the religious ethos of the organisation so that disabled people are enabled to make fully informed decisions in these areas.

## Article 22 – Respect for privacy

The Draft Initial State Report outlines that measures such as EU General Data Protection Regulation (GDPR) and Freedom of Information Act apply equally to disabled people. We call on the State to provide more information on the ‘reasonable assistance’ that is provided to persons with disabilities to utilise such measures. The State should also outline the accessibility measures that have been put in place to ensure disabled people are aware of their right to privacy and can access their information and complaints mechanisms on an equal basis with others.

We ask the State to detail the measures it has taken to ensure that State bodies and agencies are similarly respectful of disabled people’s, and their families’, right to privacy and confidentiality on an equal basis with others, and transparent access to the information held on them by the State in line with best practices under GDPR and domestic regulations, principles and legislation.

The Draft Initial State Report also references the duty doctors and medical professionals have to maintain confidentiality. The State should also outline the complaints mechanisms available should a breach of this obligation occur, the accessibility of such mechanisms to persons with disabilities and any awareness-raising campaigns in place.

We also call on the State to outline any measures in place to ensure service providers, caregivers and others who work with or support persons with disabilities are aware of their right to privacy, have received appropriate training and the role of any monitoring bodies in this regard.

## **Article 23 – Respect for home and the family**

Disabled people are less likely to receive sexual and relationship education and information on their contraceptive options when compared with their non-disabled peers. We call upon the State to outline what measures it has to address this inequality, and where they are not available, outline plans to implement such measures. We also request that information regarding the involvement of disabled people in the development of such measures be provided.

We call on the State to outline barriers to care for disabled people in the Health (Termination of Pregnancy) Act 2018, and plans to remove them under the current review. We insist that organisations of women with disabilities (OWDs) be meaningfully included in the review process. The introduction of telemedicine over the course of the pandemic has allowed greater access for pregnant people with disabilities, we call on the State to confirm that this will be retained following the pandemic.

We ask that the State clarifies whether all information pertaining to abortion provision is available in the full range of accessible formats and methods.

We petition the State to provide further information on the availability of contraception and inclusion of disabled people in proposed reforms to the Assisted Human Reproduction Bill.

We request that the State lay out any proposed concrete measures to reform parenting support for disabled parents. We call for more information on the use of Parental Capacity Assessments. We insist that the State provide details of supports put in place to support disabled people applying to foster children.

We question the omission of disabled pregnant people and disabled new parents from the national maternity strategy. We ask that the State ensure that any existing policy or frameworks are included in the State Report.

## **Article 24 – Education**

Reference is made to the Equality Act which prevents discrimination on the basis of disability, however staff, students and educators in educational establishments do not receive any disability awareness training. The State should outline how it plans to develop and implement such disability awareness training, and how it plans to include disabled people in the development and implementation of such training.

The Draft Initial State Report asserts that pupils with SEN either attend special schools or “attend mainstream with additional support”. The State should provide gender, ethnicity and disability disaggregated data on the number of students attending mainstream (with and without support) vs special schools. The State should also outline what monitoring mechanisms it has in place to ensure that the support available to students is sufficient and that ‘soft barriers’ to deter the enrolment of disabled students are not in use.

The State provides no data on the rates of practises such as seclusion, exclusion, restraint, isolation and denial of enrolment/ shortening of school days for disabled children. The State should provide this data where it is available along with details of reporting and monitoring mechanisms. Where this data is not available, the State should outline how it plans to collect this data.

We also call on the State to monitor and report on practices of denial of enrolment, ‘short’ days, classroom exclusion, seclusion, restraint and isolation to ensure that such practices comply with children with disabilities’ right to non-discrimination in education and freedom from degrading treatment as guaranteed under the UN CRPD. We encourage the State to create a regulatory framework for the use of these methods, in partnership with disabled people and their representative organisations, and to ensure that its implementation is monitored on an ongoing basis and to ensure that these methods are not disproportionately used on disabled, ethnic minority or otherwise marginalised students.

We welcome the State’s referral of the new Standard Operating Procedure for Assessment of Need for review, and encourage the State to ensure that the review process is fully informed by the principles and provisions of the UN CRPD so as to address the barriers to students’ access to educational support extant under the current and former Procedures.

The Draft Initial State Report outlines the various supports available to disabled students at different stages during their education. However, the State should also outline the supports available for students during the transition from different education levels, e.g. primary to secondary education, and include support for non-traditional educational paths, e.g.: VEC and community courses, re-training, apprenticeships etc.

The State should outline what policies, supports and funding are in place to support disabled students in accessing postgraduate education and what measures exist to ensure that students can access these supports, including access to complaints mechanisms, in all levels and types of education. Moreover, we ask that the State include information on the involvement of disabled people in the development, implementation and monitoring of such measures.

## **Article 25 – Health**

The Draft Initial State Report addresses early intervention and diagnostics for children, but we request more information on diagnostics and intervention for adults. We would particularly like information on public pathways for diagnosis for adults with autism and ADHD. This is an issue which disproportionately impacts disabled women and other gender minorities, as they are far less likely to have received diagnosis as children. There is also a lack of specialist knowledge and public diagnosis for hypermobile Ehlers-Danlos Syndrome (hEDS), which again particularly affects women as they are more likely to experience these conditions; we call upon the State to address the unequal gender outcomes resulting from current public healthcare provision, including how it will identify these gendered inequalities and measures it has introduced or, where this information is unavailable, it will introduce to improve gendered experiences of healthcare.

The barriers within health systems raised by our members in consultations are not reflected in the Draft Initial State Report. Barriers in healthcare booking systems were highlighted as an issue, with services either providing phone or text based systems with no choice. Many who took part in our consultations faced barriers to basic examinations due to lack of access or unavailability of a hoist for example.

The Draft Initial State Report should outline training for healthcare and medical staff on the human rights model of disability, and how representative organisations of disabled people are included in such training.

The issue of long waiting lists and the difference between public and private care was raised by our members, along with the regionality of access to best quality care. In some cases, people choose to pay for treatments they could not always afford. The State should provide information on how it plans to address long waiting lists which should include targets and implementation timeframes.

The lack of availability of primary care services was raised. In addition to this, many of our consultation participants spoke about access to services depending on where you are living and your postal code impacting on a timely response to medical care and treatment. Those in rural areas were particularly disadvantaged in this regard. We call on the State to include data or information on policies aimed at ensuring equity of access to care for persons in rural areas. Where data is not available, we request that the State include information on measures that will be put in place to collect this data, disaggregated on the basis of gender, ethnicity and disability.

We call for greater inclusion of information relating to older disabled women under this article.

The Draft Initial State Report does not appear to adopt measures to ensure that all persons with disabilities, particularly disabled gender minorities, have access to the full variety of health services in their own communities. The specific issue of sexual and reproductive healthcare is not given due regard in the Draft Initial State Report.

## **Article 26 – Habilitation and rehabilitation**

Participants in our consultations raised concerns at the regular and widespread use of Applied Behavioural Analysis and other behavioural interventionist therapies, particularly on neurodivergent children. We ask that the State clarify its position on the use of such therapies and outline measures to ensure that any such therapies used in Ireland are in full compliance with the principles and provisions of the UN CRPD, including respecting disabled people’s right to their identity and refraining from the use of cruel or degrading treatment as determined by the recipients of such therapies (current and former) and their representative organisations.

As outlined above, many survivors of behavioural interventionist therapies have identified their practices as inherently abusive, with research showing that exposure to such therapies increases an individual’s likelihood of developing PTSD by more than 85%[[2]](#footnote-1) and increases their likelihood of dying by suicide in later life. We call on the State to outline how it plans to incorporate the accounts and views of disabled people in their determination of which practices are identified as exploitative and abusive.

## **Article 27 – Work and employment**

Ireland has entered a reservation under Article 27 and we call on the State to outline any plans to withdraw this reservation which restricts disabled people’s opportunity to work in a number of frontline roles in the public sector.

The Draft Initial State Report notes the work of the Centre for Effective Services (CES) and a number of strategies to enhance employment opportunities for disabled people. However, DWI’s consultation participants highlighted concerns regarding lack of supports available when transitioning into employment and to those who acquire a disability while in employment. The State Report should address in detail the support mechanisms available to persons with disabilities in these regards.

We note the State’s reference to the introduction of an awareness-raising programme and training for private sector employers in the Draft Initial State Report. We call on the State to provide detail of this initiative including the establishment dates, targets for implementation and the involvement, if any, of persons with disabilities in the design and delivery of the initiative. The State should also detail in the report the involvement of persons with disabilities or their representative organisations (DPOs) in the CES’s work generally.

The Draft Initial State Report fails to describe any measures in place to ensure the accessibility of training or professional development opportunities within employment. We call on the State to address this issue within its report.

Finally, the Draft Initial State Report provides information on the public sector duty and the targets that must be achieved. However, in this section of the report the State must also provide data, disaggregated by gender and ethnicity, on:

a) the employment of persons with disabilities in the public sector,

b) the number of persons with disabilities who are unemployed

c) the number of economically active persons with disabilities, disaggregated by gender, type of work and other relevant factors, compared to the employment rates of the non-disabled population.

d) the average earnings of employees, by occupation, gender, ethnicity, age group and disability status.

We also call on the State to outline any strategies under review to make sure that accessibility improvements brought about by the switch to remote working necessary under Covid-19 restrictions will be retained and built upon for employees with disabilities, while ensuring that these improvements do not replace workspace-based accessibility requirements in employment.

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

The State’s draft report outlines the Disability Allowance payment and other related disability-specific payments. We request that further information be provided which describes any State actions in progress to address the high rates of refusal to Disability Allowance applicants which are overturned on appeal to make sure fewer applications are wrongly refused.

How will the Government address current means testing of Disability Allowance and other supports whereby the earnings of a spouse, civil partner or cohabitant may reduce the disabled person’s allowance, which has been shown to be a contributing factor in the significantly higher rates of coercion, violence and abuse experienced by disabled people, and in particular disabled gender minorities.

Disabled people are more likely to experience poverty relative to their non-disabled counterparts. Currently the rate of payment for Disability is significantly less than the temporary Covid payment. Where disabled people choose to work, they often lose access to support, establishing a poverty trap, which impacts gender minorities more. We insist that the State outline what measures it intends to put in place to address this poverty trap, and how it plans to include disabled people in the development and implementation of such measures.

## **Article 29 – Participation in political and public life**

We ask that the State outlines a plan to reform electoral laws to ensure they are accessible and in keeping with the CRPD.

While a postal vote system exists, it is difficult to access, and only available in limited ways. We ask that the State outline what measures it will put in place to extend postal vote to all people.

We have seen an increase in the number of disabled candidates over recent years, however, they have consistently raised a lack of support as an issue . The Draft Initial State Report does not include details of measures to support disabled candidates running for election.

We also call on the state to outline measures to ensure that disabled people can participate in other community organising endeavours such as school boards, tidy towns committees etc.

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

The Draft Initial State Report refers to a variety of measures put in place to ensure that facilities used for cultural, recreational, tourism or sport purposes are accessible to all persons with disabilities. This includes references to the accessibility of cultural or heritage sites and the role of the OPW (Office of Public Works). We call on the State to outline the involvement of disabled people and their representative organisations (DPOs) in the development of the codes of practice, pilot programmes and other initiatives which aim to address accessibility issues.

In relation to children and young people with disabilities, the State should outline the number of accessible play facilities available, and the guidelines in place to ensure that new-built play facilities will be available, to disabled children - in particular those facilities funded under the Capital Grant Scheme and those located in schools or public facilities. If such guidance is not currently in place the State must outline any plans to address this and plans to involve disabled children and young people in the process. The final report should also address broader access to play and leisure for disabled children and young people including inclusive sport, access to cultural initiatives and private play/recreation amenities or services.

We call on the State to outline the measures in place that ensure the accessibility of television programmes, films, theatre etc. for persons with disabilities including the funding and training provided to broadcasters or producers in this regard and the involvement of disabled people in the implementation or monitoring of such processes.

The final report should outline measures in place to support persons with disabilities to participate in sport, the arts and recreation and the funding allocated by the State to disability-specific sporting activities as a percentage of the total public funding, disaggregated by gender where possible. Particular mention should be made of funding allocated for activities which are led, developed, and organised by persons with disabilities.

## **Article 31 –** S**tatistics and data collection**

The Draft Initial State Report is very data-light, provides very little statistical data in relation to disabled people, and fails to disaggregate the data which is present based on gender, ethnicity and impairment type. We call on the State to provide such data, where it is available, and outline how the State plans to collect and disseminate this data where it is not available.

As per our most recent census data, 51.6% of those who have disabilities in Ireland are women. We know from comparative international statistics that the number of women with disabilities is very likely to be higher than this, which may indicate that we are not fully capturing women with disabilities under existing data collection processes. Thorough and disaggregated data is essential in terms of capturing the experiences of people with disabilities, particularly those who also experience additional marginalised identities in regards to their gender, ethnicity, religion, membership of the LGBTQIA+ community and so forth. In 2017 Ireland reported to the CEDAW Committee which raised the importance of robust data-collection and analysis in relation to women with disabilities. The active and meaningful participation of disabled people’s representative organisations (DPOs) in the full process of data-collection and disability-related research (including in the design, planning, implementation, analysis and dissemination of these processes) is essential in ensuring their successful outcomes.

## **Article 33 – National implementation and monitoring**

Disabled People’s Organisations (DPOs) are the only representative bodies of disabled people and should be recognised, prioritised and supported (both through funding and in terms of capacity building) by the State. We call on the State to outline its plans to facilitate this. We also ask the State to report on any measures in place to ensure that DPOs are included in all State consultation on disability-related matters and that all relevant State actors and contractors are cognizant of the distinction between DPOs and other disability-related organisations, charities and service providers and are taking appropriate steps to prioritise DPO input in their processes.

1. ‘Vulnerabilities for Abuse Among Women with Disabilities’ M.A. Novak et al, Sexuality and Disability, Vol. 19, No. 3, Fall 2001 ( 2001): https://link.springer.com/content/pdf/10.1023/A:1013152530758.pdf [↑](#footnote-ref-0)
2. ‘Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis’ H. Kupferstein, 2017: https://www.researchgate.net/publication/322239353\_Evidence\_of\_increased\_PTSD\_symptoms\_in\_autistics\_exposed\_to\_applied\_behavior\_analysis [↑](#footnote-ref-1)