



Disability Federation of Ireland's Submission to the
Department of Children, Equality, Disability, Integration
and Youth

On the Draft State Report on the UN Convention on the
Rights of Persons with Disabilities

9th of April, 2021

The Disability Federation of Ireland welcomes the chance to comment on the state's draft submission on the UN Convention on the Rights of Persons with Disabilities, UN CRPD. This initial report to the Committee on the Rights of Persons with Disabilities is an important moment for Ireland. The Programme for Government states: "Ever since Ireland ratified the UN CRPD, we have signalled to those with a disability that we are now serious about making a difference – a difference that will make things better. The ratification raised awareness of the lived experience of people with disabilities, but we have much more to do."¹

With this initial report, it's important that Ireland set a clear baseline on the lived experience of people with disabilities in Ireland. This baseline should take into account what services and programmes are available, what obstacles people with disabilities still face, where the state is doing well in delivering equality for people with disabilities, and where improvements need to be made. Only by setting this baseline, and using clear indicators, can Ireland's progress in the years ahead be properly measured.

For this submission, DFI carried out an extensive consultation process. We held a public webinar explaining the role of civil society in the state report. After that, we held three roundtables with people with disabilities, addressing the topics of physical access, access to services, and participation and consultation. We created and circulated a survey on the state report. Finally, we held a roundtable for our members, to get their feedback on the state report. All of this work is reflected in this submission.

There are a number of overarching issues identified during this consultation, that although cannot be linked to any specific Article, nonetheless require consideration by the Department. Firstly, many of those who contributed to our consultations expressed a strong view that the report falls far short of creating this sort of comprehensive overview. In a consultation that DFI held people with disabilities stated that the report did not capture their experience of living in Ireland. The lists of programmes, policies, committees and legislation read like a "talking shop" that had no relation to the experiences of people on the ground. Indeed, while the report lists an impressive number of programmes and legislation, it does little to discuss the details of implementation, or how successful Ireland's work has been to improve the lives of people with disabilities. The report suffers from a lack of data and statistics. It also fails to address the chronic problem of resource shortages. In a state where many services are resource driven, rather than demand driven, this is an egregious oversight.

In addition, participants believed that the report also fails, in many cases, to note where the state has failed to live up to its own obligations. For instance, many pieces of important disability legislation in Ireland have not been fully commenced. The report mentions the Education for Persons with Special Educational Needs Act 2004 and the Assisted Decision Making (Capacity) Act 2015 which fall into this category. No mention is made of other legislation, such as the Citizen's Information Act 2007,

¹ Programme for Government Our Shared Future, June 2020.

or the Disability Act 2005 in this regard. This report would be an appropriate place for discussions of why such legislation remains only partly commenced, and to make a firm commitment to see it fully commenced.

Drafting this report also presents an opportunity for Ireland to reflect on the current shortcomings in the way the state addresses the inequalities faced by people with disabilities. Even in its current form, the report makes clear that there is still much work to be done. Currently, different parts of government often fail to work well together in addressing the obstacles faced by people with disabilities.

The Programme for Government repeatedly emphasises implementation and collaboration.

“Improve and change services through better implementation and collaboration.”²

“Resource the National Disability Inclusion Strategy, with an emphasis on close collaboration between state agencies and civil society.”³

“In doing more, we now need to improve the services through better implementation and by working together across Government in a better way.”⁴

Currently, this report does not mention many of the commitments in the programme for government or reference the ground-breaking development of the new Disability Matters Oireachtas committee.

The Joint Oireachtas Disability Matters Committee was established on foot of a Programme for Government commitment “to assist in the monitoring and implementation of the provisions in the Convention....” It is greatly welcomed by DFI as we sought this as one of two essential infrastructural developments. There is now a mechanism at Oireachtas level to focus on implementation and monitoring.

The creation of the Joint Oireachtas Disability Matters Committee is a ground-breaking development. To be fully effective there needs to be a strong executive arm to oversee and drive this project. Being “serious about making a difference” requires active executive leadership and coordination coming from the Department of An Taoiseach.

There is no implementation mechanism operating at central government level to lead and coordinate the necessary efforts across the public sector and beyond. DFI had also sought that there be a Minister of State within the Department of An Taoiseach to provide the overall leadership and coordination that rightly must come from that Department. That proposal was not taken up and no alternative mechanism has been put in place to ensure overall project management of the work needed. This is a missing link to ensuring that there is efficient and effective execution of the commitment to implement the UN CRPD fully in Ireland.

² Programme for Government pg. 78

³ Programme for Government pg. 78

⁴ Programme for Government pg. 77

General Provisions of the Convention – Article 1-4

The first four articles of the UN CRPD cover the basic principles of the convention, as well as a state's general obligations under the treaty. Ireland uses this part of the report to detail its own history with the UN CRPD, some facts about disability in Ireland, and some of the framework to promote and protect the rights of people with disabilities in Ireland. There is no discussion of Disabled People's Organisations, DPOs, although their participation in the implementation of the UN CRPD is required under article 4.3. Many people with disabilities think that DPOs are underfunded and under-supported in Ireland.

The National Disability Inclusion Strategy, NDIS, is mentioned, but there is little detail on its implementation. This is a theme that is repeated throughout the report, with mentions of the state's commitments under the NDIS, with no discussion on how well the state is doing in meeting those commitments. Even less detail is given on the Comprehensive Employment Strategy.

No mention is made of the new Committee on Disability Matters as a UN CRPD monitoring mechanism or the Public Sector Duty, and little is said about the general obligations of article 4

Three different definitions of disability are given, Disability Act 2005; Equal Status Act 2000-18; and Census 2016. The census definition is the broadest. It does not state which definitions apply in which cases, or what the government sees as the most relevant definition in terms of UN CRPD. The Census data on the number of people with disabilities is given but this may not be the definition applied.

Article 5 – Equality and Non-discrimination

This section of the report covers the laws that protect equality and prevent discrimination in Ireland. It also covers statistics around discrimination against people with disabilities in Ireland. It does leave out some gaps in Irish law, where discrimination is still permitted. These include exemptions in the Equal Status Act for bodies such as insurance companies. These gaps allow, for instance, insurance companies to charge higher premiums to companies that employ people with disabilities. For other gaps, such as the fact that the "disproportionate burden" standard for reasonable accommodation is not universal, no timeline is given for legislation to address this problem.

There is a mention of the Centre for Excellence in Universal Design (CEUD), but it's not made clear that the work of this centre is mostly advisory, and the standards that it designs do not have automatic force in law. The statistics chosen to illustrate discrimination in Ireland are from the Household Survey, and cover how many people with disabilities felt discriminated against. This is a fairly subjective measurement, and more objective measures of discrimination in Ireland do exist. In

2018, IHREC and the ESRI worked together on a report on discrimination against people with disabilities in Ireland.⁵

Article 6 – Women with Disabilities

As with many other sections of this report, this section is very focused on the state's work, agreements and policies the state has in place, but not on the experience of being a woman with a disability in Ireland. Even looking at this list of programmes, there are clear gaps that leave out large numbers of women with disabilities. Such as:

- There is a commitment to gathering improved data and information on women with disabilities leaving institutional care moving to new models of independent living in the community. There is no commitment to studying the experience of women with disabilities who are already living in the community, or who acquire their disability later in life. This is despite the fact that these women are in the vast majority of women with disabilities.
- The report gives specific actions around greater levels of participation in public life by deaf women and girls, but no specific action to encourage greater participation of women with disabilities more generally.
- There is a commitment to “undertake further research to guide maternity services and supports for women with disabilities during and post pregnancy.” No commitment is given to provide greater support to women with disabilities who choose, or do not have the choice, to become mothers.
- A commitment to supporting women with disabilities around their general sexual health and the unique challenges they face in accessing support is required. For example, physical access to cervical testing, breast check supports (particularly mobile vans providing this service) and STI clinics. And again, the plan is for research, with no commitment to implementation. The report also does not address the difficulties that women with disabilities have accessing mainstream services for women. This includes difficulties accessing domestic violence services, including women's shelters.

Article 8 – Awareness-Raising

This article addresses raising awareness about people with disabilities, their contributions to society, and the barriers they face in society. The first problem in this section of the report is that in addition to including awareness raising about people with disabilities, paragraphs 63, 65, 71 and 72 deal with raising awareness among people with disabilities of education and employment programmes. These programmes do not belong in this article, and would be better placed under articles dealing with education and employment.

⁵ <https://www.esri.ie/news/new-esri-ihrec-research-shows-people-with-disabilities-much-more-likely-to-experience>

The point about all public sector employees receiving disability awareness training is welcomed, but there is no timeline given for this to be achieved. The report also leaves out some awareness raising campaigns that have taken place in the community. #Purplelights is a campaign to raise awareness of the International Day of Persons with Disabilities, 3 December, which is led by people with disabilities. Make Way Day, an awareness raising campaign led by DFI, is located under Article 20, while we feel it would be better placed here.

Article 9 – Accessibility

The focus of this article is all forms of accessibility, including physical, information, and services. This is obviously a very important issue to people with disabilities in Ireland. There are some areas where people with disabilities had praise for Ireland's accessibility. These include:

- Many people had positive experiences with the Luas, although there is not always space for a wheelchair user to board
- People had positive comments on the changes to the DART, including work to reduce advance notice and improve the lifts. Although a few people still had problems using the DART, including trouble with unmanned stations and broken SOS buttons
- The Customer Service Officers on Irish Rail were welcomed
- The pandemic programme in rural public transport, which included transport to medical appointments and delivery of shopping, was very welcomed.
- Dublin Bus's Travel Assistance Scheme is very popular, although participants felt it did not receive enough state support, and were disappointed the state has not expanded the programme beyond Dublin Bus.

However, the report once again fails to capture the experience of people with disabilities living in Ireland. In this case, one problem is that the report is very Dublin focused, with less attention given to the accessibility challenges experienced by small towns and rural areas in particular. There are still many issues around the accessibility of buses in Ireland, including in Dublin. Bus stops are not always accessible, and neither are buses. People are unhappy about many recent changes, such as the removal of yellow bus stop poles in Dublin, and the new single decker buses, which are seen as less accessible.

There is also little discussion of the problems with Part M of the building regulations. While this sets minimum standards, most people agree these standards are not good enough to be truly accessible. Any plans to reform Part M should be discussed in the report. There also needs to be more discussion around the access officers. While many access officers are dedicated and do good work, it is not a full-time position. They also do not have their responsibilities and duties clearly defined in law, and often work with no budget. None of these problems are clear in the report.

Article 11 – Situations of Risk and humanitarian emergencies

One of the most important subjects found under this article is the state's response to the COVID-19 pandemic, and how that response included people with disabilities. There are a number of gaps in how the report addresses this issue. These include:

- The NPHET Vulnerable People sub-group with disability representation is mentioned, but it does not make it clear that this has been disbanded and was only in place for the early stages of the pandemic. The High Risk Subgroup which replaced it and does not have disability organisation representation is not mentioned.
- The success of the enhanced summer programme is overstated. The report does not give figures on participation and the eligibility criteria is unclear.
- The report does not go into much detail on impact of school closures on children with additional needs or measures put in place (other than guidance notes).
- As with schools, the information on service closures is not very specific.
- Income support measures for the general population are detailed but it doesn't draw attention to lack of specific measures for people with disabilities.
- The report also leaves out issues such as the inequity between PUP and similar payments put in place and Disability Allowance; difficulties for people with disabilities who are high risk when their workplace re-opens in terms of availing of supports, and other issues faced by people with disabilities. The report only gives the rate of one of the payments listed.

Article 12 – Equal Recognition before the law

It is disappointing that Ireland intends to keep its declaration on Article 12. By declaring its intention to allow the continuation of substitute decision making in circumstances where the UN CRPD would not support its use, Ireland is failing to fully implement the convention. When states such as Ireland, that claim to support human rights, take declarations such as this, they provide cover for other states to dismiss the authority of the UN, and continue to ignore human rights. Many states have taken no such declaration to Article 12, and they do not seem to have suffered any ill-effects from not doing so.

Article 13 – Access to Justice

This article deals with access to justice, including ensuring that the court system and the police are disability-friendly and accessible to people with disabilities. In the report, clear gaps in ensuring access to justice can be seen. The discussion on access to the court system is almost exclusively focused on physical accessibility. It does include induction loops, but does not cover other accessibility problems. These could include:

- Lack of accessible information
- Lack of disability awareness among court system staff

- Negative attitudes and stigma towards people with disabilities

There is also a lack of discussion around supporting defendants with a disability, including access to special consultation areas, sign language interpretation and other aids to support them in their defence.

We do welcome the work the Gardaí have begun on hate crimes, and look forward to seeing the outcomes of this work.

Article 14 – Liberty and security of the person

This article of the convention addresses the right of people to not be detained arbitrarily, or based on their disability. Ireland has stated that it will keep its declaration to this article. DFI would like to discourage this, for the same reasons given to the declaration on Article 12.

Ireland admits in this report that current Irish law does not meet the standards of Article 14. New legislation is being prepared, but no timeline for this new legislation is given. There is also no discussion of how the Assisted Decision Making (Capacity) Act 2015 will affect the right to liberty. The report should also be updated on the progress on the review of the Mental Health Act.

Article 16 – Freedom from exploitation, violence and abuse

As in many other sections of the report, this section gives a list of legislation, policies and commitments, without discussion on their effectiveness, or what the experience of people with disabilities is. There are not many statistics in this section, to illustrate the problem of violence against people with disabilities. There is also no mention of the lack of hate crime legislation in Ireland.

Article 17 – Protecting the integrity of the person

In this section, a longer discussion of how the Assisted Decision Making (Capacity) Act 2015, and its full commencement will affect the way that people with disabilities exercise their right to bodily integrity, would be useful. There is also no discussion of the need for accessible information in ensuring full consent to, for instance, medical procedures.

Finally, the section of the report on sterilisation and forced abortion only covers abortion. It does not address any protections—or the lack of them—to forced sterilisation in Ireland.

Article 18 – Liberty of movement and nationality

The discussion of immigration in this section of the report does not cover what kinds of reasonable accommodation or support are available to people with disabilities

going through the citizenship process or getting their passport. It also does note that people with certain disabilities may be refused entry to Ireland, and there is no suggestion that this will be changed to conform to the requirements of the UN CRPD.

There is also no discussion of Direct Provision, the impact it has on refugees with disabilities, and the plans to change the Direct Provision system.

Article 19 – Living Independently and being included in the community

There is no discussion in this section of the report of the under-resourcing of many of the services that people with disabilities rely on to live independently. There is also no mention of the fact that there are very few entitlements to these services in Ireland. For the most part, there is no statutory right to receive the services that a person needs to live independently. This fact is not made clear in the report. People with disabilities will only receive them if the resources are available, and at present they are not. This service delivery model, and our broader level of implementation, resources and cross-departmental coordination in the area of housing, does not support true choice and control for people with disabilities, and has led to shortages of critical services for independent living, such as Personal Assistants.

There are a number of gaps in the report. These include:

- The report states that Housing Disability Steering Groups are found in all local authorities, but as of this time, not all local authorities have their HDSG fully operational, and relevant actors do not always attend meetings.
- Time To Move On is mentioned, but the report does not mention that this programme was meant to be concluded by 2018. If possible, the 2020 figures should also be added to the report.
- The report mentions that The National Housing Strategy for People with Disabilities was extended from 2016 to 2020. There is no discussion of what obstacles the strategy encountered that required an extension. Any details about the post 2020 strategy would also be useful.
- There is no discussion about a path to independent living for people with disabilities who are currently living with family.
- There is insufficient data given on what has been specifically and concretely delivered and implemented in the area of housing for people with disabilities.
- There is no discussion of the shortage of accessible social housing.
- In Ireland, it is often more difficult to receive services that support independent living in rural areas. This does not appear in the report.
- There is no mention of the disproportionate amount of people with disabilities who are homeless (27% of the homeless population) or analysis of how accessible homelessness supports are to people with disabilities.
- There is no mention of the over 1,300 people with disabilities under the age of 65 who are currently living in nursing homes, and how this will be addressed.
- While Housing Adaptation Grants are mentioned, there is no analysis of difficulties people with disabilities experience in trying to access the Grant, or the fact that the level of grant falls below current building costs.

- There is no analysis in how the lack of resources in community-based disability services including PA and home support services hampers access to independent living. For example, many people with disabilities cannot access social housing offered by their local authority due to a lack of support package of PA hours from the HSE.

Finally, Article 19 also states that community services, including mainstream community services, should be accessible to people with disabilities. This report only covers disability specific services. This omission should be corrected, and a discussion on the accessibility of mainstream services should be included.

Article 20 – Personal mobility

This article covers both access to mobility aids, such as wheelchairs, and the ability to move through the community. While this covers various government programmes to improve personal mobility in Ireland, it's missing the way that people with disabilities experience these programmes. In DFI's own work, we have found that people with disabilities are unhappy with the way that Disabled Person's Parking Permits or Cards are distributed. People found them hard to apply successfully for, and felt that the criteria and the way the applications were carried out were based in the medical model. They had the same feelings about the ways aids and appliances are handled. For instance, currently people must apply for a VAT refund when they purchase equipment need for their disability. This creates a barrier for people with disabilities living in poverty.

Furthermore, the report does not mention programmes that support mobility that have been cut. The mobility allowance, and the recent end of the Citizen's Information assistive technology database Assist Ireland are not mentioned.

On the other hand, while there has been general praise for the Garda programme Operation Enable, which looks for the abuse of disabled parking bays and parking permits, this programme is not mentioned in the report.

DFI's campaign Make Way Day is also mentioned here. While DFI welcomes the mention, we feel that this would be better placed in the section on Awareness Raising. We would also like to be phrased in a way that makes the active role of people with disabilities clear. Make Way Day is based on people with disabilities actively pointing out the obstacles they face when traveling around their community. Without the work and participation of people with disabilities, Make Way Day would not be possible.

Article 21 – Freedom of expression and opinion and access to information

There are a number of exceptions to the right to information in Irish law for people with disabilities, and while these exceptions can be seen in the report, the report does not deal with how the exceptions may have an impact on the lives of people with disabilities. These exceptions include the fact that people with a visual or

hearing impairment will only receive accessible information if they request it. For people with intellectual disabilities, only information deemed relevant to them is made available in easy to read formats. How the state determines what information is relevant is not explained.

In the section on the use of sign language, the report does not discuss the experience of using sign language in Ireland. There is a shortage of interpreters, they are expensive to hire, and the state only covers the expense in certain cases. The difficulties faced in hiring interpreters are an important part of the experience of people in Ireland with a hearing impairment.

Article 22 – Respect for privacy

While this section of the report lays out the protections for privacy in Ireland, it does not address the particular challenges people with disabilities might face in exercising their right to privacy. For instance, while the EU General Data Protection Regulation, GDPR, is mentioned, there is no discussion of measures the state has taken to ensure that people with disabilities understand their rights under GDPR, or any supports they are given to exercise those rights.

The report also fails to acknowledge how inadequate services can have an impact on the right to privacy. As an example, physically inaccessible private consultation rooms in medical services, Citizen's Information offices, and social welfare offices can deny people with disabilities the right to a private consultation. Those living in institutions and unsuitable accommodations can also have their right to privacy compromised by their living situation. In institutions, people with disabilities can be expected to share communal spaces, even when they would prefer to be alone. In unsuitable accommodation, a person can be confined to the downstairs of a house, and may therefore sleep or perform other private functions in communal spaces.

Article 23 – Respect for home and the family

This article addresses support for home and the family. It particularly addresses the right of people with disabilities to make choices about their family life, including when and whether to have children, and the right to raise their children.

In paragraph 273, the report mentioned that the Marriage of Lunatics Act 1811 will be repealed. It is our understanding that the law has been repealed, and this is out of date.

There are also gaps in the report. These include:

- the report states that anyone who meets the criteria to adopt or foster a child can do so, but never states whether the criteria for adoption in particular will exclude people with certain disabilities.
- Census status on mothers with disabilities are presented, but not analysed. For instance, the report states that 63.7% disabled women are mothers

compared to 46.9% of non-disabled women. This difference suggests that family planning and access to sexual education may not be equal.

- The report does not mention statistics on children of parents with disabilities/ and children with disabilities being taken into care, and what this suggests about the sufficiency of current supports for parents with disabilities and children with disabilities.

It is also worth noting that while the focus of the article is on supporting parents with disabilities to have their own family, the focus of the report is on supports for children with disabilities.

Article 24 – Education

The focus of this section of the report is on education. Once again, there is a focus on legislation and policy, with little discussion of how people with disabilities experience these policies, or how successful they are. Gaps that exist in this section of the report include:

- The links between education and other areas such as health, employment, and poverty are not really explored. For example, the report does not go into how issues/delays with Assessment of Need impact access to educational supports.
- The NCSE Progress Report 2019 is mentioned, but the state report does not state that the report found that Ireland is at risk of being in breach of the UN CRPD in relation to education. The state report should also be updated with the policy advice that was due in 2020.
- Some gaps in terms of the statistics used:
 - Narrowing of educational attainment gap of 3% for people with disabilities between Census 2011 and Census 2016- but the actual figures on what the gap still is that are in Census 2016 are not given.
 - Figures given on numbers and percentage of children with SEN in special schools and classes, but the figure and percentage in mainstream school is not given.
 - Number of students with disabilities in FET given but not the percentage.
- States how many pre-school age children benefit from AIM but no overall sense of the level of participation in early years education by children with disabilities.
- No analysis of the issues that occur at transition points between different stages of education and while exiting education, such as the lack of consistent supports that follow the person.
- No discussion of the need to make education accessible to people with sensory and multi-sensory disabilities, such as deafblindness.
- No mention of the fact that students with disabilities in special schools do not have access to career guidance counsellors, unlike children in mainstream schools, or plans to remedy this.

In addition, the report has very little detail on further education. It also notes that the EPSEN Act is not fully commenced, but gives no timeline or commitment to commencement.

Article 25 – Health

This article focuses on the importance of equality in healthcare for people with disabilities. As in most sections of this report, the focus is on listing policies and policy document, with no details on how these are implemented. There is also no discussion of issues around resourcing in healthcare. The Disability Act/Assessment of Need is mentioned in one line, without any mention of the fact that Ireland is not meeting its legal requirements laid out in the Act. Strategies to ensure that cancer screening programmes are accessible to people with disabilities are mentioned, although there have been many issues with women with disabilities ability to access cervical screening. In general, mainstream health services are at times inaccessible to people with physical disabilities, as they may lack equipment such as hoists. This is not discussed in the report. The report also does not discuss obstacles that people who are non-verbal face in the health care system.

There is also no analysis of the resource gaps in disability-specific health and social care services, particularly community-based services including PA and home support, and therapy services. The state report needs to give a better sense of the levels of unmet need, and plans to remedy this.

Article 26 – Habilitation and Rehabilitation

This article is about providing services that help people with disabilities attain and maintain maximum independence in their lives. As with other articles, programmes to provide these services are mentioned, but there is little discussion of the implementation, the experiences of people with disabilities using these services, or statistics on how many people can access these services. There is also no discussion of the resourcing of these services, and whether current resources meet demand.

Currently, there are gaps and problems in services, that are not reflected in the report. These include

- People must travel to urban places to access many rehabilitation services, although the UN CRPD requires that services be equally available in rural areas.
- Access to assistive technology is very costly, even for mainstream assistive technology. There is no right to funding for assistive technology
- Transport to get to services is often not provided, especially in rural areas
- People have to work around the routine of the service they are given, people aren't given personalised supports.

Article 27 – Work and Employment

This article addresses equality in employment for people with disabilities. This is very important for Ireland. The current employment rate for people with disabilities in Ireland is almost 20% lower than the EU average, one of the lowest rates in the EU. Partly as a result, people with disabilities in Ireland are far more likely to live in poverty, with a consistent poverty rate of almost 20%, one of the highest in the EU. The report describes many programmes to improve employment, but does not discuss implementation or provide data on how well these programmes work. There is also evidence of a high level of discrimination in employment in Ireland. For at least the last three years, the highest number of queries to IHREC on discrimination in employment have related to disability.⁶ The report does not discuss the affect of the pandemic on the employment of people with disabilities, who have faced unique challenges.

Article 28 – Adequate standard of living and social protection

As mentioned above, the poverty rate among people with disabilities in Ireland is disproportionately high – in 2019 almost 1 in 5 people lived in consistent poverty, while 37.7% were deemed at risk of poverty. People not at work due to disability or illness in Ireland are three times more likely to be at risk of poverty or to live in consistent poverty than the general population, and these rates sadly doubled over the past decade, during a time of economic recovery in Ireland. Therefore, it is disappointing to see that, as in other sections of this report, this section mainly lists a series of policies and existing social protection schemes, without providing any discussion of their implementation, or data on how well these policies have worked, or on how their impact is monitored and reviewed in terms of a positive impact on the shockingly high poverty levels mentioned above.

The report does not even acknowledge or mention the high poverty rate, nor does it set out a clear plan to work to reduce it in the coming years in order to deliver on the rights governed by this Article. For example, paragraph 403 mentions that a study on the cost of disability took place in 2020, and paragraph 404 mentions an NDA report that is over 15 years old. It is relevant to note that people with disabilities and disability organisations have been highlighting, and documenting the problems caused by the extra cost of disability in Ireland for over 20 years, and one academic study from 2015 has estimated that this cost could be up to €207 a week (meaning it is more than the €203 provided to those who live on Disability Allowance). Many organisations and individuals have been calling for this to be addressed and acknowledge through a cost of disability payment for years. None of this background is acknowledged in the report.

Other issues not addressed in the report are some of the gaps found in Irish services. Two examples of this are:

⁶ According to IHREC's annual reports

- There is an age limit on eligibility for a medical card for a child whose carer or parent is getting a domiciliary carer's allowance. This is despite the fact that some children have progressive conditions, and needs increase with age.
- Certain conditions are not included in the criteria for the long term illness scheme. This seems arbitrary, and deprives some people with long term illnesses of the benefit.

Article 29 – Participation in political and public life

This section covers the right to vote, participate in politics and other aspects of public life. Once again, the personal experience of people with disabilities is not present in the report. While the report highlights measure to make voting more accessible, people with disabilities still report significant problems in voting. These include:

- Returning officers not having the training to assist people with disabilities
- People in wheelchairs cannot reach the high platform in the private polling booths, might have to vote at a table where they can be seen
- Using and keeping your postal vote registration is difficult, as it must be renewed every year. The local authority is supposed to contact you to see if you still need a postal vote, but they sometimes forget. The postal vote must be signed off by a doctor, which is very much in the mindset of the medical model, and is outdated.
- Also, all of the measures to make voting more accessible mean nothing if people are unaware of them. There is no mention of measures to make people with disabilities aware of their rights.

Many areas covered by the article are left out entirely. There is no discussion of supporting people with disabilities to join political parties or run for office. There is no discussion of supporting people with disabilities to join or form advocacy organisations and other NGOs. The new Disability Participation and Consultation Network is mentioned, but that is a body designed to improve consultation with the state, and would be better placed under Article 4.

Article 30 – Participation on cultural life, recreation, leisure and sport

This article addresses the participation of people with disabilities in cultural life and sports. Once again, while there is a list of programmes and policies, there is no sense of how these are implemented, and no data to support how well they work. In some cases, such as the programmes set out in paragraphs 414 and 427, programmes seem to be in danger of setting up a separate space for cultural life for people with disabilities, rather than integrating people with disabilities into mainstream cultural life.

Article 31- Statistics and data collection

It is important that a state have complete and up-to-date statistics around the lives of people with disabilities, in order to ensure that their rights are being respected and they are treated equally in society. A lack of data can hide problems. This section of report details sources of statistics, but does not discuss how accurate the sources might be, or what is done with this data to inform policy. There is no mention of Ireland's problems disaggregating data on disability. There is also no discussion of efforts to make data on disability accessible to people with disabilities.

Article 33 – National implementation and monitoring

This section addresses the national framework that Ireland has set up to guide the implementation of the UN CRPD, and the framework to monitor that implementation. This is an important part of this convention, as a strong framework here makes implementation easier and more likely. The report states that DCEDIY is the focal point of the implementation framework, but does not make it clear that this is only an administrative appointment, and is not set out in statute. A statutory appointment would set out the powers and responsibilities of the focal point in greater detail, and give the opportunity to provide a budget for this work. The report also lists the NDIS as the force tying together government work on the UN CRPD, but the NDIS will expire at the end of this year, and there is no discussion of its replacement. Article 33 itself provides for a clear replacement: Ireland could appoint a coordination mechanism. DFI has consistently proposed that the Department of An Taoiseach is the relevant department to coordinate government actions around the UN CRPD, in keeping with its overall departmental role. Choosing not to have this coordinating function is a missed opportunity that will cause a disproportionate expenditure of energy for little progress as has been the case with the NDIS.

It is disappointing that the government has not managed to pass the Disability (Miscellaneous Provisions) Bill 2016 that would officially appoint IHREC as the monitoring mechanism, despite this bill having been drafted in 2016. However, the report also fails to acknowledge the work that IHREC has already done in anticipation of this appointment. This includes the creation of the Disability Advisory Committee, made up of members of civil society, a majority of whom have a disability, who advise IHREC on their work on the UN CRPD. In fact, the report completely fails to address 33.3 at all. This sub-article is on the role of civil society in monitoring implementation, and no information is given on its implementation.

Conclusion

As noted at the introduction of this submission it is critical that Ireland uses this initial States Report to set a clear baseline on the lived experience of people with disabilities in Ireland. This baseline should take into account the totality of the issues relating to the delivery of services and programmes currently available within the State, identifying where there is evidence the obstacles people with disabilities still

face, where the state is doing well in delivering equality for people with disabilities, and where improvements need to be made. Only by setting this baseline, and using clear indicators, can Ireland's progress in the years ahead be properly measured

Although the draft report provides a comprehensive overview of the programmes in place, it fails to identify the challenges currently impeding the implementation of these programmes and legislation. Without this information it will be difficult to truly evaluate State success over the coming years.

If the report, and the UN CRPD in general, were a higher priority for the government, many of the problems found in this report could have been avoided. This is one reason that DFI has suggest that the Department of An Taoiseach should act as a coordinator, and provide a project management function to the complex, multi-departmental work of implementation and reporting. Ideally, this sort of work should be provided with the coordination and drive needed from the centre of government administration.



DFI is about making Ireland fairer for people with disabilities.

We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We do this by supporting people with disabilities and strengthening the disability movement.

There are over 120 member organisations in DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.

DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research, Policy Development and Implementation
- Organisation and Management Development

Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.

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