



Disability Federation of Ireland

**Opening statement from the Disability Federation of Ireland, DFI,
to the Joint Oireachtas Committee on Disability Matters**

Tuesday 20th April 2021

Cathaoirleach,

I, along with my colleague Dr Joanne McCarthy, wish to thank the Committee for this opportunity to present today. We also welcome our colleagues from the Disability Participation and Consultation Network of which DFI is one of the four funded members.

This Committee is a critical step following ratification of the UN CRPD. DFI was heartened to see the commitment in the "Programme for Government Our Shared Future" along with other commitments to advance implementation.

I now make a number of points to give some background to this statement.

The Disability Matters committee has the critical task to drive implementation of the CRPD within the Oireachtas. Yet it requires a complementary mechanism through the Department of An Taoiseach, namely the operation of a project management function to ensure effective and efficient implementation across the overall civil and public service. This is urgently required.

Thankfully, there are a growing number of organisations in the disability area. Some called "disabled persons organisations", others, "service provider" or "voluntary disability organisations". All of these have a valuable role to play.

The 640, 000 people with disabilities in Ireland have a shared reality of poverty and exclusion. Exclusion from so many things that others rightly take for granted. See Appendix A. There are obstacles in accessing health, personal social services and other public services such as education, transport, housing, employment, general community participation, to be able to live independently and family formation.

Throughout the growth of the disability movement there are many examples of organisations working collectively, they form into collectives or umbrella groups. From time to time there are also alliances developed to work on particular issues and often to engage with the State on policy or legislative matters.

The UN CRPD requires nothing less than the will and preference of people with disabilities to be front and centre and equally that all organisations, be they state, voluntary, community or private work together to make inclusion happen.

DFI has been involved in the implementation processes of successive national disability strategies. If Ireland uses the same approach to

implementing the UN CRPD it will not succeed. Project management of the implementation needs to operate from the Department of An Taoiseach.

The Programme for Government commitments to implement the UN CRPD came after the arrival of the Covid pandemic. An ambitious and well-funded implementation programme is needed, and we expect it, for the remainder of this Dáil.

Now to specifically address today's agenda.

Progress in implementing the CRPD and the Optional Protocol and the States response in delivering compliance to the UN CRPD

Since this Committee has been established some important foundations to progress implementation of the UN CRPD have been put in place. Moving the Disability Services Programme from the Department of Health to the new Dept of Children, Equality, Disability, Integration and Youth is significant. It reflects the principles underlying the UN CRPD that disability is not necessarily a health issue; it also sets in motion the transfer of the core funding to disability services, worth over €2.2b to the new Department. For the first time it ensures the Department who has responsibility for delivering on the overall government programme for disability, previously the NDIS and now the UN CRPD, is also the Department that holds the funding allocated to disability. Having a specific Cabinet Minister with disability responsibility is also a notable development.

In addition to these process developments, in December the State published its first draft Initial Report on the UN Convention on the Rights of People with Disabilities. As a funded member of the DPCN we consulted with people with disabilities and their organisations, gathering their views as to the progress the State has made in implementing the CRPD. Please find linked here [our submission on the State's UN CRPD draft report](#).

Through this consultation several significant implementation issues of relevance to this Committee have emerged:

- While Ireland is rich in disability relevant legislation, strategies and programmes, we are constantly weak in implementation
- Many pieces of legislation remain only partially commenced. These include the Education for Persons with Special Educational Needs Act 2004, the Assisted Decision Making (Capacity) Act 2015, the Citizen's Information Act 2007, and the Disability Act 2005.
- In general, there is a lack of reliable data around people with disabilities and their lives, which would be useful in informing policy and to track the impact of future disability measures. Lack of

baseline data will make it very difficult to track outcomes and impact as we progressively implement the UN CRPD.

- Ireland continues to have one of the highest poverty rates among people with disabilities in the EU- the Government must address this as a matter of urgency, and as an initial step raising the Disability Allowance payment to equal that of the Pandemic Payment, acknowledging the true cost of living in Ireland.
- Ireland has yet to ratify the Optional Protocol to the UN CRPD. This has given people with disabilities reason to feel that the Government does not take their concerns seriously, as it will not enable them to bring these concerns to the UN.

The State's response to delivering compliance to the UN CRPD therefore can be best characterised as policy strong but lacking overall project management. This critical omission can however readily be addressed, by putting into operation of a project management function in the Department of An Taoiseach to drive and oversee the implementation.

The Disability Participation and Consultation Network and ensuring the participation of people with disabilities in decision making

As part of its efforts to include people with disabilities in decision making, the government has funded the DPC Network. This network has four funded members: DFI, the DPO Coalition, AsIAM, and Mental Health Reform. There is also a coordinating member, Inclusion Ireland. The goal of this network is to involve people with disabilities in government decision making. While all the members of the DPC Network welcome its establishment, and the commitment to inclusion and consultation it represents, it has experienced some growing pains as a new body. Very soon after its beginning, we started our first task, the consultation on the draft state report. There was little time to adjust to working together as a unit, and even less time to consider how to include the over 100 new members. These problems were compounded by the unanticipated quick turnaround needed on the consultation. We also have concerns around the funding level, especially given how many of the organisations involved are volunteer-led.

In addition to issues of State compliance the participation by people with disabilities is central to successful implementation. The UN CRPD clearly puts persons with disabilities front and centre in relation to their will and preference and fully respects their agency as decision makers. They must be actively involved in every stage of building and testing the pathways as all other entities engage with them to create the outcomes. It also requires many other actors within the State to actively support inclusion.

The UN CRPD firmly places responsibility on all of us, across public, private and civil society, to think, plan and respond to the expressed needs of people with disabilities. In addition to working with our DPO members, DFI also recognises that organisations working with people with disabilities have a critical support role to play. These are the organisations that often have ongoing contact and relationships with individuals. On that basis they are well placed to play an important role in supporting the implementation of the UN CRPD.

The impact of COVID-19 on people with disabilities

It is difficult to fully assess the impact of COVID 19 on people with disabilities as Ireland, unlike other countries did not gather data on people with disabilities with COVID outside of residential settings. However, the low presentation of COVID 19 in day and residential services is notable, and testament to the efforts of people with disabilities and their services during very difficult times. It is important to remember that even before COVID disability services were carrying combined deficits of over €40 m, and that these issues will have been exacerbated as a result of COVID and remain to be addressed.^{1, 2}

There are several ongoing challenges with respect to COVID that should be noted here today:

Impact of Service and School Closures and Reductions

The impact of closures and reductions in day service on people with disabilities has been immense. Over time, the resilience of people and families has been stretched. We recognise and welcome the funding provided to date to support day services to resume including the €7.5m funding to increase provision in September. There is a welcome focus on increasing capacity in day services from 40% to 50-60%. However, learning from the pandemic has exposed issues such as digital poverty and access to assistive technology so that all people with disabilities can benefit from access to digital services, mitigating against the impact of service disruption.

¹ COVID-19 has made this situation even worse, particularly for some of the smaller organisations who are heavily dependent on fundraising income. A survey of a sample of just 20 of our member organisations last year found that essential services were threatened for 55%. There was a collective loss of €7 million among just those 20 organisations. We would expect that the impact on organisations has grown worse over time. There is a real risk that organisations could move from being 'vulnerable' to 'unsustainable.'

² Publishing the Department of Health's capacity review of disability services will go some way towards demonstrating the level of investment that is needed. The commitment to multi-annual funding in the HSE Corporate Plan is very welcome and would have a significant impact in allowing services to plan for the future, rather than responding when situations have become emergencies.

In addition to day services, respite services have also been severely impacted, with a notable reduction or in some cases a cessation of service. In some cases, respite facilities have been converted to COVID-19 isolation facilities. There has been welcome funding for emergency home care packages, but many families are still struggling. The fear, anxiety, and stress that COVID brought to people, their families and carers cannot be overstated.

Impact on Mainstream Health Services

The reduction in mainstream health services has also had a significant impact on people with disabilities. Many people with disabilities have significant co-morbid health conditions. Services including diagnostic services, regular reviews, therapies, primary care services, neurological services, mental health services etc have been impacted. Prior to Covid people with disabilities were experiencing long delays accessing essential health and neurological services. This has worsened since COVID-19. As of March 2021, there are 22,825 people on the outpatient neurology waiting list. 11, 424, over half, have been waiting for more than 12 months.³ The redeployment of staff to areas such as contact tracing, testing and supporting the vaccination programme has we suspect further compounded these delays and we would ask that the Joint Oireachtas Committee Meeting on Health consider exploring this issue further.

Learning from COVID- the need for reform

COVID-19 has demonstrated the need to reform disability services. It exposed many of the weaknesses in our existing models of service. There are still 2,914 people with disabilities living in congregated settings. There are over 1,400 people with disabilities under 65 living in nursing homes. These people were, because of their living arrangements, placed at much greater risk to COVID. These heightened risks and necessary service closures have emphasised the critical need to move to models of more personalised and tailored supports in line with the expectation under Article 19 of the Convention. To support people to live ordinary lives in ordinary places increased investment and reallocation of funding to services such as Personal assistant (PA) and home support services, and personalised budgets will be required⁴.

Budget 2021 was the second year in a row that included a modest increase in PA hours. This was welcome, but still falls far short of meeting the levels of unmet need. The commitment in the HSE Corporate Plan to prioritise person-centred services in line with the UN CRPD was also very welcome.

³ <https://www.ntpf.ie/home/outpatient.htm>

⁴ Far too many people with disabilities find themselves unable to access housing offered by their local authority due to a lack of a personal assistance package from the HSE. Only 0.3% of people with disabilities have access to a personal assistant service.

Addressing the Cost of Disability

The most recent Survey on Income and Living Conditions, SILC, data from 2019 showed that 37.5% of people not working due to illness or disability are at risk of poverty, a level of poverty which is clearly unacceptable. People with disabilities live with significant extra costs of disability including medical costs, transport costs, accessible housing, specialist diets etc. A response to this level of poverty is long overdue, with widespread recognition of the inadequacy of the current rate of payment of the Disability Allowance at €203 a week. The sense of injustice was further compounded when the State introduced the Pandemic Unemployment Payment, the highest rate of which is €350. There is a distinct difference between the DA payment and the recognised cost of living as reflected in the PUP. It is no longer acceptable that we continue to expect people with disability, who carry significant additional costs due to their disabilities, to live on this inadequate rate.

Vaccination Programme

Ensuring that people with disabilities and those who support them, including family carers and frontline staff, are vaccinated in a timely manner is now a major priority.

People who attend residential and day services have been vaccinated. This is a significant achievement which the HSE are to be commended for. There are still questions regarding whether this will be extended to people in all disability services including those who receive PA and home support services. Many of those in receipt of these services have many complex co-morbid health conditions. Completing this programme and vaccinating all people with disabilities in disability services would have a tremendous impact. We would like to see a guarantee from NIAC, the Department of Health and the HSE that this cohort people who receive PA and home support services will be prioritised for vaccination.

There are also many people with disabilities who are not linked to any disability services but have significant health vulnerabilities. It is welcome that after significant advocacy people in the 'very high risk' and 'high risk' groups were included in the vaccination programme, in cohorts 4 and 7.

However, there is much anxiety and confusion among people who are vulnerable to COVID-19 about who is included in these groups, and how and when they will be contacted for the vaccine. As GPs will play a significant role in this, it is essential that they have appropriate information and are given the necessary flexibility to carry out this process.

Another important group who has been left out of the vaccine priority groups is family carers. NIAC have based their vaccine allocation groups on the risk of hospitalisation and death to the person, and carers will be

vaccinated according to their age group and health conditions. However, this approach fails to recognise the symbiotic relationship between carers and the person they support. Family carers carry out many of the same roles as healthcare professionals, the only difference is that they are not paid for this. If a family carer was to become ill with COVID-19, it would have a significant impact on the person with a disability and could lead to their hospitalisation or an emergency residential placement. There is also a significant risk of COVID-19 to the person they support, particularly in the case of family carers of children under 16 who are too young to be vaccinated. This has been recognised in the UK, where family carers have been included in the vaccine prioritisation list.

Concluding remarks

DFI has been involved in the implementation processes of successive national disability strategies. If Ireland continues to use the same approach to implementing the UN CRPD it will not succeed.

The Department of An Taoiseach need to operate a project management function to ensure effective and efficient implementation across the overall civil and public service. This is urgently required.

The Programme for Government commitments to implement the CRPD came after the arrival of the Covid pandemic. An ambitious and well-funded implementation programme is needed, and we expect it, for the remainder of this Dáil term. The upcoming budget will tell a lot.

UN CRPD requires nothing less than the will and preference of people with disabilities to be front and centre and equally that all organisations, be they state, voluntary, community or private work together to make inclusion happen.

The current reality of poverty and exclusion needs to be replaced by people with disabilities having sufficient income and full inclusion to live life with dignity in Ireland.

One year into Covid and thousands of people and families have been added to the disability community. These are ordinary families who have to deal with two traumas, COVID-19 and trying to come to terms with disability and it's impacts.

COVID-19 will recede, living with a disability will not.

Thank you.

APPENDIX A

These statistics illustrate the depth of persistent poverty and exclusion that people with disabilities routinely experience:

- There are 643,131 people with disabilities in Ireland. By 2026, this number is estimated to increase by 20%.⁵
- Poverty rates for people with disabilities in Ireland are 10% higher than the EU average. Ireland ranks amongst the worst five countries in Europe.⁶
- Ireland has the lowest employment rate for people with disabilities in the EU. It is almost 20% lower than the EU average of 50.8%.⁷
- 27% of the homeless population have a disability- double the rate of the general population.⁸
- 2,914 people with disabilities remain living in congregated settings.⁹
- Over 1,400 people with disabilities under the age of 65 are inappropriately placed in nursing homes.¹⁰
- Only 0.3% of all people with disabilities get a Personal Assistance Service.¹¹ There is no legal right to personal assistance in Ireland.
- 13% of those on Carers' Allowance are over 70.¹²
- Voluntary organisations that provide services to people with disabilities are carrying €40m+ deficits.¹³

⁵ Census 2016 and NDA (2018), Disability Statistics.

⁶ CSO, SILC (2018) op cit, EDF (2020) p.18-19.

⁷ EDF (2020), Poverty and Social Exclusion of People with Disabilities: European Human Rights Report p. 48.

⁸ Census 2016.

⁹ <https://www.hiqanews.com/the-experiences-of-people-with-disabilities-in-congregated-settings/>

¹⁰ DCU and DFI (2018), The situation of younger people in nursing homes in Ireland- phase 1.

¹¹ HSE (2017), Service Plan 2018.

¹² Department of Employment Affairs and Social Protection (2020). Statistical Information on Social Welfare Services: Annual Report 2019.

¹³ Joint Oireachtas Committee on Health (2019).



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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