



Disability Federation of Ireland

Impact of COVID-19 on people with disabilities and the
disability sector

Monday 29 June 2020

Executive Summary

It is the view of DFI that, since the outbreak of this pandemic, there has been a commitment to ensuring that measures are in place to protect people with disabilities from the threat of COVID-19 and respond to the specific needs of those who contracted the disease. For this we are deeply appreciative. The health ethical guidelines demonstrate this principle in relation to any situation where lack of capacity to treat might become a reality. Thankfully Ireland has avoided this situation in the first phase.

However, as we face into the next phase of this pandemic it is critical that we reflect on some of the key learnings from our experience to date, including:

- Serious lack of PPE, particularly for use in the community;
- Our already highly inadequate community-based services;
- Financial deficits and the extra costs for organisations to resume service provision;
- Digital poverty and the impact this has on the disabled community;
- Anxiety and fear among persons with disabilities and their families, in relation to health and care workers visiting their homes;
- Serious regression due to people not having access to their educational, social and health services;
- The resilience of family members and carers.

As we move into the COVID-19 recovery phase there is a need for a specific plan for people with disabilities to ensure the necessary infrastructure and investment is available to support ongoing efforts. This plan must address:

- An adequate budget allocation to respond to existing funding deficits in disability services and to fully fund the cost of reopening and delivering services in the context of COVID-19.
- A ringfenced investment in a community supports package for individuals and families living in the community.
- The COVID-19 Stability Fund must be adequately resourced and extended to address the funding needs of small to medium community-based disability organisations that rely heavily on fundraising income.
- The lack of preparedness for people with disabilities, already in employment, with health conditions that compromise them in relation to the infection and return to work;
- The need for long term service reform based on the learning from COVID-19 and the UN CRPD;

- The need to invest to reduce poverty of people with disabilities and sustain services post-Covid.

Introduction

DFI welcomes the opportunity to raise disability specific concerns arising from COVID-19 and in the post COVID-19 recovery planning. There are 643,131 people with disabilities living across Ireland, making up 13.5% of the population.¹

Ireland is experiencing an unprecedented challenge that is testing individuals, families, communities, and the state itself, as we collectively respond to the many impacts of COVID-19. The short-term impact of this public health emergency has been severe, with people with disabilities severely impacted. The longer-term impacts, socially and economically, are also likely to be seismic.

The United Nations have highlighted the need for a disability-inclusive Covid recovery and response to the crisis.² As we begin to plan for the recovery we must reflect on the experience of people with disabilities, and commit to support all people equally, according to their needs, in the coming post COVID-19 phase. A renewed focus on recovery, and on rebuilding a more supportive, inclusive society must be harnessed.

At this point, we feel it is important to reflect on where we need to go and learning so far. We welcome this opportunity to raise a number of specific issues that must be considered now and as we plan for the future. We must reflect on the learning from the past months to allow us to be better equipped for any future spikes in infection rates, and to ensure that the post Covid recovery is equitable to people with disabilities.

COVID-19 Response for People with a Disability

What Worked

The disability sector responded well to COVID-19. Out of 1,100 residential centres for people with disabilities there were 14 confirmed deaths linked to COVID-19. There was no outbreak in 75% of settings, and where there

¹ Census 2016

² <https://www.un.org/development/desa/disabilities/news/dspd/covid-19-2.html>

were outbreaks 25% were Covid-free after 28 days.³ This is testament to a number of positive measures put in place.

There was positive, open and regular engagement between disability umbrella organisations and the HSE at a national level. The umbrella organisations were able to raise issues that arose quickly and there was a swift response. The HSE were able to ensure that important guidance and communications were disseminated in a timely fashion to the umbrellas' member organisations on the ground. The collaborative approach modelled the engagement advocated for in the Independent Review Group examining the role of voluntary organisations (Catherine Day report).

The national disability umbrellas pushed for a seat on the NPHET Vulnerable People Sub-Group which was granted. This was valuable in escalating issues that required a national response.

The HSE produced guidance specific to disability services based on the NPHET and HPSC public health guidance. This made the high-level public health guidance relevant to disability settings.

The low level of infections, clusters and deaths in disability settings is a testament to the hard work of voluntary organisations, staff and the HSE. Infection prevention and control guidance were adopted and implemented rapidly.

Learning

Initially, PPE was difficult to access for disability services. This was a particular issue for services supporting people in the community e.g. PA or home support services who in some cases were not prioritised by the HSE at a regional level. Local authorities and COVID-19 response forums were not always willing to provide PPE to disability organisations as they viewed it as the responsibility of the HSE. This highlights the structural impediment of working across state agencies. People with disabilities and carers also found it difficult to access PPE. These difficulties have alleviated as the supply of PPE has improved. However, it is important that a supply is built up for disability services in the event of a spike in infections.

Funding was a major issue hampering services' ability to respond, and could threaten them long-term. Already prior to COVID-19 services faced deficits of over €40 million. In 2020, an additional €20 million (1%)

³ <https://www.rte.ie/news/coronavirus/2020/0603/1145260-coronavirus-deaths-disabilities-residential-setting/>

efficiency cut was imposed. Following announcement from outgoing Minister for State, Finian McGrath on Friday 26th June it appears now that this will be reversed, and funding returned to organisations where it was cut. However, immediate clarity is needed on this from the Department of Health.

The additional costs and loss of fundraising income due to COVID-19 have worsened this funding crisis. The Charities Institute of Ireland COVID-19 Impact Survey conducted in late March found that:

- The average projected loss per charity is €650,000, i.e. 40% of a charity's income.
- The overwhelming majority of respondents have already cancelled a vast array of events, campaigns or other activities (89%).
- 35% of respondents are considering or have made redundancies.

A survey of a sample of 20 of our member organisations found similar results:

- 37% are concerned that they won't be viable after 6 months.
- 50% have laid off or are preparing to lay off staff.
- Essential services are threatened for 55% of organisations due to loss of fundraised income.
- The sample of 20 expect a potential fundraising loss of over €7 million in 2020. The sector-wide loss will be substantially higher.

Many DFI member organisations that applied for the crisis funding being distributed by local authorities were unsuccessful or found ineligible because they are majority funded by the HSE and are not viewed by the Local Authorities as part of the community response.

The COVID-19 stability fund must be adequately resourced and extended to address the funding needs of small to medium community-based disability organisations that rely heavily on fundraising income.

Additionally, COVID-19 has highlighted some of the inequalities that exist between Section 39 and Section 38 organisations. For example, section 38 employees were eligible for COVID-19 sick pay but section 39 employees were not. The wider issue of section 39 and section 38 inequalities and categorisation needs to be examined.

Daily Life of People with a Disability

Under 65s in Nursing Homes

There are over 1,300 people aged under 65 inappropriately placed in nursing homes,⁴ due to disability. The new Programme for Government has committed to addressing this, and we hope to see immediate progress. The inappropriate placement of under-65s in nursing homes is directly linked to the lack of statutory entitlement to community services. The statutory Nursing Home Support Scheme (Fair Deal) is often the only viable option open to people who acquire a serious disability or whose disability worsens considerably. The Programme for Government commits to a statutory homecare scheme. A statutory entitlement to PA services for people with disabilities is also needed.

Nursing homes witnessed over 50% of all deaths in Ireland. There were seven deaths of people under 65 and nine of people between the ages of 55-64 confirmed to be due to COVID-19. Thankfully this was a relatively low number, although it also shows that people with disabilities under 65 in nursing homes were more at risk than people with disabilities in residential settings.⁵

There were further impacts of COVID-19 on people with disabilities under 65 in nursing homes outside of infection. Many of this cohort were used to a degree of independence, with some going to work. Due to restrictions to prevent and curb outbreaks, people were confined to their rooms. This would have had a severe impact on the mental health of people under 65 in nursing homes, already impacted by their inappropriate placement.

Investment in community services and accessible housing for people with disabilities is needed to end the practice of accommodating under 65s in nursing homes. Cross-departmental working is required, particularly across the Departments of Health and Housing, to address this issue.

Reduction in Services

Due to the COVID-19 restrictions, resources were concentrated on residential services. This decision was made due to the public health emergency, but health is a gateway to inclusion and without specialist services people with disabilities lost their independence. Over the long

⁴ <https://www.rte.ie/news/health/2018/0808/983809-nursing-homes/>

⁵ 14 deaths among 8,422 people with disabilities in residential services (0.2%); 16 deaths among 1,300 people under 65 in nursing homes (1.2%)

term, this cannot be sustained without severely impacting people's daily lives.

Day services were closed and respite extremely curtailed apart from emergency responses to families in crisis. Some people with disabilities living with family members who were able to take on an additional caring role had their PA and home support services removed under a prioritisation system adopted during the pandemic.

In other cases, people with disabilities with high risk conditions chose to temporarily give up their PA/home support hours to reduce the number of people entering their household. These families may not have anticipated how long COVID-19 would remain with us and may now be struggling to cope. Other family members who took on care may be returning to work.

The prioritisation and adequacy of PA and home supports needs to be urgently reviewed now as family members experience excessive burn out and/or are required to return to work.

Disability services put in place innovative approaches to deliver services remotely and respond to COVID-19 for example:

- Increased phone contact. Many services have rung all of their service users/members, including those who they may not have had contact with since diagnosis to check in;
- Emotional support from family support workers;
- Linking people to online/phone mental health supports;
- Online group wellness/cognitive behavioural therapy programmes;
- Online social events e.g. Zoom coffee mornings;
- Sourcing autism-friendly masks for people they support;
- Setting up professionally moderated online support groups for people with disabilities and carers;
- A range of online interventions including one to one supports;
- Working in collaboration with the HSE and other organisations to

Innovative approaches have helped to alleviate some of the mental health impacts of Covid. Greater online contact should supplement in person activities in the future to reach those who find it more difficult to leave their homes to attend support/social groups due to their disability.

However, a huge amount of disability services that are in-person and cannot be delivered any other way. In person contact is central to building relationships between the person and the organisations' staff. Some people with disabilities cannot engage to the same extent in remote/online activities for a variety of reason including digital poverty, low digital literacy, co-ordination difficulties in using phones and laptops/tablets, living in areas with low internet connectivity.

Educational Supports

School closures have had a major impact on students with disabilities, both in special and mainstream schools and classes. Children regularly benefit from a range of therapeutic and other developmental supports. Supports in schools include physiotherapy, occupational therapy, speech and language therapy, sports and socialisation. The loss of these supports has brought regression which will hamper overall progress if not responded to as soon as possible. Special Needs Assistants providing support to children with disabilities over the past number of weeks via a HSE scheme has been welcome, however delays due to issues such as Garda Vetting has caused frustration.

The announcement of health and education led summer provision schemes were welcome to families and children with disabilities. It is important that these schemes support all children with disabilities, particularly all children whose primary carer receives Domiciliary Care Allowance.

Students with disabilities in Further and Higher education have also been impacted. In a survey by AHEAD of 601 students with disabilities in Further and Higher education 58% of students disagreed or strongly disagreed with the statement 'I am coping well with learning from home.'⁶

Next Phase

Need for a Community Plan

As we move into the COVID-19 recovery phase there is a need for a plan for people with disabilities living in the community. Over 95% of people with disabilities do not live in residential settings.⁷ DFI's experience of working on the NPHE Vulnerable People sub-group was that the initial focus was on long-term residential settings. As society re-opens, more focus is needed on people with disabilities living in the community whose risk of exposure to COVID-19 will increase.

While the data on Covid in disability residential settings is positive, data on how COVID-19 affected people with disabilities in the community was not published. Information on underlying conditions among Covid deaths

⁶ <https://www.ahead.ie/userfiles/files/shop/free/Learning%20from%20Home%20During%20Covid-19%20-%20A%20Survey%20of%20Irish%20FET%20and%20HE%20Students%20with%20Disabilities.pdf>

⁷ Based on HSE Service Plan 2020 and Census 2016.

was published, but without a breakdown of the specific conditions. It is important that this information begin to be collected and published.

A ringfenced investment in a community supports package for individuals and families living in the community is also needed to ensure that the additional cost of PA and home supports services are addressed.

Employment Issues

As society re-opens, challenges are presenting for people with disabilities in employment as their workplaces re-open. Many people with disabilities are categorised as high risk or extremely high risk if they contract COVID-19 including people with severe respiratory or neuromuscular conditions such as cystic fibrosis, Parkinson's Disease, muscular dystrophy etc.

People who are high risk or very high risk have been advised to cocoon and stay at home to protect their health since the onset of the COVID-19 crisis. This advice remains in place, and it is anticipated that those who are high risk may need to stay at home for months, or even longer, into the future.

Many of this cohort have been in receipt of the Pandemic Unemployment Payment while their workplaces have been shut. However, the current advice of the Department of Employment Affairs and Social Protection is that high risk individuals will no longer receive the Pandemic Unemployment Payment or be eligible for the Enhanced Illness Benefit once their workplace re-opens. This means it will be financially impossible for many high-risk people to follow the public health advice to cocoon. This issue also affects family members living with high risk people.

The Pandemic Unemployment Payment or Enhanced Illness Benefit should continue to be paid and/or be extended to all high-risk people for whom working from home is not possible.

Clear guidelines are also needed for high risk people related to returning to work. A campaign aimed at employers to ensure they make reasonable accommodations for high risk people or people cohabitating with high risk including allowing them to work from home where possible would also be valuable.

Increased Service Delivery Costs

Planning is underway as to how services that were stopped during Covid can resume. HSE Working Groups have been established, and guidance is

being provided to services. There are a number of issues that will need to be resolved.

Services that are re-opening will face additional costs now, e.g. costs of screens, carpet uptake, deep cleans, PPE to provide the same level of service as before. Social distancing requirements will also reduce productivity. In addition to the wider funding crisis facing disability services already discussed, these specific issues will need to be addressed in services' budgets.

Some disability services staff were redeployed to Covid related activities e.g. contact tracing. In order to return to the previous level of service, these staff will need to return.

Over 90% of people with disabilities are not supported through these models of support i.e. residential, day, PA and home support services.⁸ Disability services that operate outside of traditional models, such as the below examples, need more direction and guidance on service resumption:

- Information and Advice/Helplines
- Family Support
- Social Programmes/Community Integration Programmes
- Individual Advocacy
- Local Support Groups
- Aids and Appliances/Assistive Technology
- Education/Training
- Employment-related services
- Holidays/Outings

Early recovery of services is of vital for persons with disabilities and their families. However, it is also important to look long-term and think about what is needed to improve and reform services. The UN Convention on the Rights of Persons with Disabilities, UN CRPD, must be at the centre of all planning for disability services. The publication of the Capacity Review of Disability Services and multi-annual investment to provide certainty to services and respond to needs are also vital steps.

Economic Recovery

The last time Ireland faced a systemic financial crisis the vulnerable and the poor suffered, with severe austerity wreaking havoc on living standards and pushing a cohort of people into, or further into, poverty.

⁸ Based on Census 2016 and HSE Service Plan 2020.

People with disabilities were particularly vulnerable to the impact of these austerity measures. The poverty rate of people with disabilities doubled from 2011. Even now 21.3% of those not at work due to illness or disability live in consistent poverty, a rate which is almost four times higher than that of the general population (5.6%).

Disability affects more people in the lower socioeconomic groups than others, and over time it further erodes income and opportunities for the families who live with it. This is on top of the acknowledged extra cost of living with a disability. To avoid a further slide into poverty, the state needs to urgently act to support people with disabilities.

Ireland, thankfully, has the capacity to borrow to sustain services. This makes economic sense as the cost of regression due to curtailed services would require enhanced service provision in years to come. Regression would mean that the return on that investment, in terms of independence and wellbeing, would be significantly reduced. Invest now and save later.

Conclusion

DFI and our member organisations are keen to progress the implementation of the UN CRPD in partnership with government policy. Progress has to be made here, and in a reformed way. We must continue with some of the innovative approaches adopted during the crisis, such as better use of technology. We must learn from what worked well during Covid, and from what could have been done better to support people with disabilities into the next phase and beyond.



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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