



Disability Federation of Ireland

Non-COVID-19 Healthcare

Wednesday 1 July 2020

Executive Summary

People with disabilities access to health services, including disability services and mainstream health services has been considerably impacted by COVID-19. There are a number of issues that it is important to reflect on in order to facilitate a greater access to healthcare services both now and in the long term.

Issues in relation to specialist disability services include:

- The need for 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;
- 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 need for long term service reform based on the learning from COVID-19 and the UN CRPD.

People with disabilities have experienced difficulties accessing mainstream health services. Issues to be considered include:

- Examination of ongoing redeployment of staff to COVID-19 related areas.
- Guidance for communicating with Deaf and Hard of Hearing people while wearing PPE.
- The impact of COVID-19 on already stretched services such as neurology.
- The need for additional resources to respond to COVID-19 rehabilitation needs to avoid negatively impacting patients requiring neurorehabilitation.
- The need to appropriately resource the National Neurorehabilitation Strategy.

COVID-19 has added to the mental health needs of people with disabilities and carers. This is just one aspect to a wider increased demand on services. Issues to consider include:

- Understaffing of mental health services.
- The need for greater recognition of co-morbidity of disability and mental health services, including accessible services and better integration between disability, community and mental health services.
- The need to implement and appropriately resource the new mental health policy Sharing the Vision.

Telehealth and telecare are being increasingly adopted in both disability and wider health services as a way to continue providing services. Issues to consider include:

- Positive impacts of telehealth including facilitating greater access to those who find it difficult to leave their homes, and in reducing the risk and anxiety of contracting COVID-19.
- Those who will find it more difficult to engage in telehealth including people experiencing digital poverty, those with co-ordination difficulties and people with lower digital literacy.
- The need for investment in assistive technology, and the introduction of an 'AT Passport.'

Introduction

Healthcare for people with disabilities encompasses a number of areas. Firstly, disability specific health services including residential, day, PA and home support services. Many people with disabilities also access mainstream health services in relation to their specific condition or disability including therapies, consultants, primary care, neurorehabilitation etc.

The World Health Organisation has advised that, not only are people with certain disabilities more at risk if they contract COVID-19, but also people with disabilities are disproportionately impacted from the disruption of ongoing health services caused by the pandemic.

Ongoing access to health services are vital for people with disabilities as investing in health allows for access and participation beyond health. It facilitates equal access to education, housing, public transport, employment etc. In other words, access to health services allow people with disabilities to have an independent life.

Disability Services¹

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

¹ For further information on specialist disability services, see also our submission to this Committee from 29th June 2020 on the 'Impact of Covid-19 on People with Disabilities and the Disability Sector.'

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.

Innovative online and phone supports have been put in place by services. 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. Also, some people with disabilities cannot access remote supports to the same extent, as will be discussed further later in the submission.

Financial Issues

Funding is a major issue threatening the continued delivery of disability services. Already prior to COVID-19 services faced deficits of over €40 million. In 2020, an additional €20 million (1%) efficiency cut was imposed. Following announcement from the 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. This is essential to sustain vital services for people with disabilities.

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.

Resuming Disability Services

Planning is underway as to how services that were stopped during COVID-19 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-19 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.² 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
- Health and well-being programmes
- 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.

Mainstream Health Services

Access to Mainstream Health Services

Many people with disabilities receive health services in relation to their specific condition outside of the core disability services programme. In some cases, this is managed through primary care/GPs, and in others it also encompasses care in acute hospitals. These types of mainstream health services include:

- Ongoing management by consultants who specify in the specific disability/condition;
- Therapies including occupational therapy, physiotherapy, speech and language therapy etc.;
- Neurological services;
- Primary care management of condition;

² Based on Census 2016 and HSE Service Plan 2020.

- Diagnostic testing.

Access to these health services has been impacted by the hospital capacity and infection prevention and control measures introduced due to COVID-19. Rare Diseases Ireland conducted a survey of 176 people with rare diseases and their family members, with a range of different health needs.³ Disease categories included neurology/neuromuscular, immune system, endocrine (hormone), lung, metabolic, eye, musculoskeletal, rare intellectual disability, cardiovascular, haematological (blood) and other types of rare disorders. The study found that:

- 73% were worried about their personal health;
- 56% of respondents were cocooning, with almost 50% choosing to do so due to personal concerns about their health and well-being;
- 26% were encountering difficulties accessing medicines and medical supplies.

The sources of concern about personal health cited were varied and included:

- Deteriorating health;
- Safely accessing healthcare if or when needed;
- Accessing medicines/medical supplies;
- Worry about risk of exposure to COVID-19 and impact of COVID-19 on their underlying condition.

The redeployment of staff to COVID-19 related roles is understandable but has an impact on capacity in other areas. This is particularly relevant for those who specialise in respiratory conditions for example, which has an impact on people with conditions such as cystic fibrosis, muscular dystrophy etc. Hospital patients with cystic fibrosis, a condition that makes people high risk should they contract COVID-19, have expressed concerns about infection risks due to staff going between COVID-19 and Cystic Fibrosis wards.

People who are Deaf or Hard of Hearing who rely on lipreading have experienced difficulties communicating with healthcare staff wearing PPE. Guidance is needed to address this issue.

Impact of Loss of Fundraising Income

Voluntary organisations play an essential role in providing health services to people with disabilities outside of 'traditional' services such as residential, day, PA/home support etc. In some cases, voluntary organisations fund medical posts in the community or within acute

³ Rare Diseases Ireland (21st May 2020). *Living with a Rare Disease in Ireland during the COVID-19 Pandemic*.

hospitals, such as nurses or other specialist medical staff. These posts are often partially or entirely funded through fundraising income. If this income is not replaced, it would be a disaster for the people who rely on these services.

Access to Neurological Services

Neurological services were already under-resourced prior to COVID-19. Now, they face even more pressure. As of the end of May 2020, 22,400 people were awaiting an outpatient appointment for neurology. 10,058, 45% of people, were waiting longer than 12 months.⁴

Research by the Neurological Alliance of Ireland on the impact of COVID-19 over 600 patients and carers nationwide found that 26% of patients had significant challenges in accessing neurological care, including outpatient appointments, diagnostic testing and ongoing treatments delivered in a hospital setting.⁵

Early neurorehabilitation is vital to long-term recovery. According to the Neurological Alliance of Ireland, Ireland has only half of the rehabilitation beds needed for a population of its size, all of which are concentrated in the Dublin area. Waiting lists for the only National Rehabilitation Hospital in Dún Laoghaire frequently exceed 300 patients at any one time with waiting periods of up to six months.

COVID-19 has caused a further need for rehabilitation beds, as some people who contracted the virus have serious rehabilitation needs. Anecdotally, there are concerns that this may impact timely provision to those with neurological disabilities. The recovery window is at its optimum within the first two years for conditions such as acquired brain injury.⁶ The need for rehabilitation for COVID-19 patients must be met through increased resources. Furthermore, the pre-existing shortage in neurorehabilitation beds and facilities, and neurology staff must be addressed. The Programme for Government committed to implementation of the National Neurorehabilitation strategy. The necessary resources must be provided to make this commitment a reality.

⁴ National Treatment Purchase Fund (28th May 2020). *Outpatient Waiting List by Speciality*.

⁵ Neurological Alliance of Ireland (May 2020). *COVID-19: The Impact on People with Neurological Conditions and Family Carers*.

⁶ <https://www.thejournal.ie/neurorehabilitation-services-ireland-5034423-Mar2020/>

Communication

The WHO advises that health authorities can reduce the barriers for people with disabilities who need continuing access to health services during the crises by providing accessible information, establishing targeted information hotlines and communicating through relevant disability organisations and networks.

Mental Health

COVID-19 has had a major impact on the mental health of people with disabilities and family carers. This has been particularly prevalent among people who have been cocooning. The isolation already experienced by some people with disabilities has been exacerbated. There is a huge amount of anxiety, both around fears of COVID-19 itself and around lack of services. Family carers who have had to provide care in place of services for a long time in place of services have also experienced negative mental health impacts. 62% of respondents to Rare Diseases Ireland's survey reported that COVID-19 was having a negative impact on their mental health.⁷

Frontline workers such as family support workers have reported encountering vastly increased mental health difficulties particularly among younger people and adolescents. This includes in some cases severe mental health needs, including suicidal ideation. Services for people with disabilities and carers have adapted their services in a number of ways to respond to the increased mental health needs. Examples include:

- A group wellness programme via Zoom delivered by a CBT therapist
- One to one counselling with mental health professionals
- Emotional support from family support workers over the phone
- A professionally moderated online support group for family carers
- A range of online interventions include one to one support
- Social media support groups

Some people though will require specialist mental health supports. Mental health was already understaffed by 20% prior to COVID-19.⁸ The increased need is likely across the whole of society, and not just people with disabilities. Adequate mental health provision then will be of even greater concern over the coming months, as demand increases.

⁷ Rare Diseases Ireland (21st May 2020). *Living with a Rare Disease in Ireland during the COVID-19 Pandemic*.

⁸ Oireachtas Committee on the Future of Healthcare Report (May 2017)

The mental health needs of people with disabilities were already increasing prior to COVID-19. Over the past two decades the prevalence of co-morbid mental and physical diseases have increased dramatically.⁹ The prevalence of mental health conditions among people with intellectual disabilities may be four to five times higher in comparison to the general population. A report published by The Neurological Alliance (UK) in July 2017 found that 46% of people with a mental health condition also have a long-term physical health condition and around 30% of people with a long-term condition also have a mental health condition.¹⁰ People with disabilities require mental health services that are accessible to them, for example:

- Mental health supports in physically accessible environments
- Available at home and/or online for those who find it difficult to leave their homes
- Accessible information on mental health services
- Cognisant of communication differences e.g. ISL interpretation available, staff experienced in communicating with people with speech and language difficulties etc.
- Staff experienced in interacting with people with behavioural differences outside of those caused by mental health conditions e.g. due to intellectual disability, autism etc.
- Integration between services for people who have co-morbid mental health difficulties with another type of disability.

Ireland's mental health policy, *A Vision for Change* was published in 2006, and since then its recommendations have only been partially implemented. While it made specific recommendations for the development of services for people with intellectual disability who have co-morbid mental health difficulties, little to no provision was made for people with physical, sensory or neurological conditions and a co-morbid mental health difficulty. The new mental health policy launched in June, *Sharing the Vision*, is an improvement, with more recognition of the need for integrated and a community-based approach. It is vital that *Sharing the Vision* is implemented and adequately resources to have the necessary impact.

⁹ Norman Satorious, 'Comorbidity of Mental and Physical Diseases: A main Challenge for Medicine of the 21st Century' (2013) 25(5) *Shanghai Archives of Psychiatry* 68-69.

¹⁰ E. Chesney, G.M. Goodwin, and S. Fazel, 'Risks of all-cause and suicide mortality in mental disorders: a meta-review' *World Psychiatry* (2014) 13(2) p 153-60.

Telehealth

Online and phone supports

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 by phone;
- Virtual home visits via video;
- Online social events e.g. Zoom coffee mornings;
- A range of online interventions including one to one support.

Innovative approaches have helped to alleviate some of the mental health impacts of COVID-19.

Outside of the disability sector, telehealth supports have also been provided, such as:

- Phone and online group and one to one counselling;
- Phone consultations by GPs and consultants;
- Video genetic counselling.

Online supports have enhanced service provision for some people with disabilities and increased their ability to participate. For some, particularly those with conditions that make them high risk should they contract COVID-19, the availability of services online/by phone reduces anxiety around entering hospital buildings, primary care centres etc. Where services have not been made available online, this has caused concern. For example, people with rare diseases have expressed concerns about having to attend hospitals for their prescriptions.

Greater online and phone 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. In addition to the issue of digital poverty, people with communication and co-ordination issues can find it difficult to manage talking on the phone and engaging virtually. Furthermore, some services can only be delivered in person.

Digital Poverty and Assistive Technology

Many crucial services are now being delivered online because of COVID-19 restriction. However, in many cases those most marginalised and in

need of support, lack the digital equipment or Wi-Fi to access services. People with disabilities, who may require specific assistive technology, software or training, to access online supports, are particularly disadvantaged.

The additional cost of purchasing assistive technology or accessing specialist training can prove unattainable for people with disabilities, 38% of whom are at risk of poverty.¹¹

In 2016, DFI worked with Enable Ireland to produce a discussion paper on Assistive Technology in Ireland. It highlighted the need for investment in the provision of assistive technology and advocated for the introduction of an "AT Passport" to support users to access training and the supports they need.¹² Four years on, access to technology is more important than ever for marginalised groups.

The National Disability Authority have stated that the role of assistive technology is important in enabling telecare and telehealth supports, which achieve even more relevance in situations such as the current one, where people may prefer not to visit health centres or GP surgeries in order to mitigate the risk of infections, or where some services might only be available remotely.

This is evidenced by the establishment of "digital poverty" sub-groups by Community Response Forums at local authority level. Indeed, in some cases, local authorities have made the decision to award grant funding to local community groups working to reach socially isolated people, specifically for the purchase of devices and other digital technology supports.

The National Disability Authority advises that there may be valuable learning from current implementation of solutions regarding assistive technology that could be applied in the future as a route to maximising the independence of persons with disabilities living in their own homes in the community.¹³

Conclusion

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.

¹¹ EU SILC 2018.

¹² DFI and Enable Ireland (2016). *Assistive Technology for People with Disabilities and Older People: A Discussion Paper*.

¹³ National Disability Authority (April 2020). *NDA Advice: Specific Issues for Persons with Disabilities regarding implications of Covid-19*.

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 and other health services were badly impacted. The state needs to urgently act to sustain people with disabilities' access to health services, including disability, mental health and other mainstream services.

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.

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-19, 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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