



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

# **The impact of Covid-19 on people with intellectual disabilities and the disability sector**

**June 2020**

**This document is written in font 12 Verdana in line with Inclusion  
Ireland plain English guidelines**

# About Inclusion Ireland

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Established in 1961, Inclusion Ireland is a national, rights-based advocacy organisation that works to promote the rights of people with an intellectual disability.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

## Introduction

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At the beginning of the Covid-19 period many health and social care services, including disability day services closed to people with intellectual disabilities because of the Covid-19 pandemic.

At the time, Inclusion Ireland outlined the importance of putting in place additional supports for people with disabilities during this period<sup>1</sup> and that actions specific to this group needed to be taken by Government, disability services, communities and people with disabilities themselves and their families<sup>2</sup>.

One of the key areas that needs addressing is related to the suspension of day services for individuals with a disability and their families across the country. Inclusion Ireland surveyed the people who use these services and their families on the impact the closure of services has had on them and the supports they have received in this time.

There has been also been a suspension of children's disability services, such as occupational therapy, which has been affecting the development of children, who are regressing in many cases.

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<sup>1</sup> World Health Organisation (2020). Disability considerations during the COVID-19 outbreak.

<sup>2</sup> Inclusion Ireland (2020) COVID-19 and Intellectual Disability, Supporting people with intellectual disabilities and their families

There is also cause for concern regarding the situation facing residential institutions, not only in relation to further outbreaks, but also regarding the lack of clarity in the reporting of figures from disability residential settings on a regular basis.

This cessation of many services has had significant negative effects on people affecting the wellbeing, independence and mental health of people with disabilities and their families during this time.

Ireland has ratified the UNCRPD. It is vital that people's rights are respected and promoted during this period and that the Government adheres to Article 25 of the Convention by ensuring access to health services to people with disabilities.

## **Disability 'day service' provision**

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In mid-March Disability day services closed to people with intellectual disabilities with a small number of exceptions. In May and early June, Inclusion Ireland surveyed the people who use these services and their families on the impact the closure of services has had on them and the supports they have received in this time. In total, 291 family members answered our survey and 55 people with intellectual disabilities responded to an easy-to-read version of our survey giving a total response of 346.

According to Inclusion Ireland's survey, contact between services and the people they support has been variable, as 54% of family respondents indicated that they had little or no contact or support from Day Services during the lockdown. The 54% breaks down to 15% had no contact, 5% were told they could get support in the event of an emergency or crisis and 34% indicated that they occasionally got a call to ask how they were getting on.

On the other hand, 22% of people had regular contact and support from staff by phone, a further 16% had regular online support for activities and learning, 6% had occasional home visits from staff and 2% had direct access to their day centre.

One third of people with intellectual disabilities who answered the survey said they have had little or no contact from their service.

Q7 What contact or support are they getting from the day service since it closed?



**People told us**

“An odd text message, nothing else for 10 weeks”

“Hugely disappointed with the service and HSE. Absolutely forgotten about with very little to offer either support to the family who care for them 24/7”

“None - just a box ticking phone call and our vulnerable relative was left to their devices.”

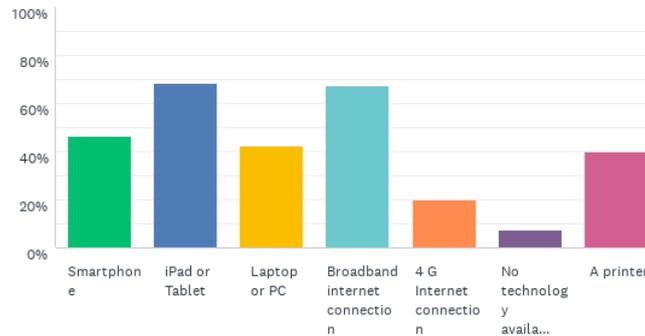
“Send out a pack once a week - magazine, activities etc and a call”

“Staff member calls 2 times a week to go for a walk in the locale and to collect DA (disability allowance) from Post Office”

As contacts between services and people who attend the service have been mostly remote in manner due to public health guidance, we asked people about their access to technology and their capacity to use it. Most people with an intellectual disability have access to iPads, smart phones and laptops but 7% of people had no access to any form of technology at home.

In the comment section of the question on the ability to use technology, 56 respondents (19%) stated that the person they support could not use any of the technology options identified due to the level of their disability. A further 6 people (2%) indicated that they could only access any computer-based technology with substantial ongoing support. So, 21% of the people supported could not use basic information technology equipment and software, even when it is available.

Q4 Does your family member have access to any of the following in their home? (tick any options that apply )



### People told us

“There is online activities, but unsuitable to ‘Pats’<sup>3</sup> level of needs”

“It took them 7 weeks to do work on zoom. They sent links to my daughter. I asked for hard copies to be sent. She gets 2hours a week!”

“As my child is non-verbal and severely autistic with complex medical needs, he is unable to participate or understand online learning”

“WhatsApp photos of the clients/friends in the day services and the photos of staff saying hello and they are missed”

“Weekly phone call from class teacher Weekly class zoom meeting Weekly post”

People with intellectual disabilities have had to adjust to life mainly in the home during lockdown. Family members said the main activity was watching TV (72%) and Listening to or playing music (60%) and 71% of people with a disability reported greater participation in exercising.

In commenting on this section, a few respondents identified excellent support from services (online learning and online physiotherapy and speech therapy). Many people expressed their frustration of little or no contact with services compounded by the significant additional stress of full-time caring without external stimulation or activities. Virtual contact was also identified as a support that did not work at all for those who are non-verbal or with complex disabilities and support needs.

<sup>3</sup> Person’s real name not used to protect identity

# The impact on people's lives

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The impact the closure of day services has had on people's mental health cannot be understated.

The Covid-19 crisis, restrictions and closure of day services is clearly having a significant impact on the mood and feelings of the people who are being supported by disability services. In terms of mental wellbeing, 38% of respondents indicated an increase in behaviours of concern, 36% indicated an increase in loneliness and 33% an increase in anxiety for their family member. People also reported increases in anger and people feeling withdrawn. For people with intellectual disability, loneliness was a significant issue for 56% of respondents.

However, 22% indicated that their family member is actually happier at home, and in some instances, this was giving rise to concerns that the return to day service and new routines might be quite challenging. People with intellectual disabilities reported slightly higher levels of happiness at home at 30%.

Other respondents indicated significant concerns about regression in skills during this period.

## **People told us**

"Happy at first but now anxious at times and not sleeping at all some nights."

"Much more withdrawn, very worrying. All gains in confidence and independence to date unravelling as we speak."

"Happy at home but also is missing social aspect of meeting staff and friends"

"Very bored and unstimulated"

"Definitely very happy at home but desperately missing his friends and teachers"

"It depends on the day. Some days can be brutal, but others are ok."

"Biggest change is sleeping routine. He stays up until 2 or 3 am and it's hard to get him up in the morning as he has nowhere to go"

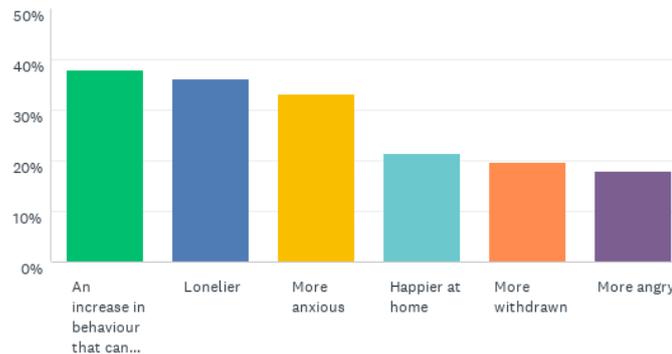
"Suffering from stomach problems in last month ... doctor suspects anxiety from effects of missing friends & normal day services"

"Self-harm, not sleeping, lashing out"

“Teary and patches of depression from an otherwise cheerful and happy woman.”

“Lonely till we got on zoom and he is happy now but misses his job on Thursdays”

Q8 Have you noticed any significant change in your family member's mood or feelings since the day service closed (tick any that apply)



## Recommendations on day service provision

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1. Guided by and adhering to public health advice, adult day services for people with an intellectual disability should reopen in line with the Roadmap for Reopening Ireland, on a par with equivalent services and facilities for the general population. Day services are education and training facilities for adults including school leavers with disabilities. As set out in the Roadmap for Reopening Ireland, all adult education facilities may reopen from June 29<sup>th</sup>, 2020.
2. Our consultation indicates that direct face to face supports from their service are a clear priority for people with intellectual disability. There is also a clear preference amongst people who are providing support at home for direct contact with staff and for advice and support, rather than for virtual online contact. Face to face support is the only form of day service that will work for people with complex disabilities.

3. The resumption of Adult Day Services must not mean a reduction in service hours or supports for people with intellectual disability or a greater reliance on family members or carers.

Almost 40% of individuals who responded to our survey attend day service with support at a level of 1:1 support. A significant number of individuals are supported at a ratio to enable attendance in small groups and a small number or respondents 10-15% require little individual support. This level of individual support, combined with the increasing number of smaller community-based settings established under the New Directions policy, should mean that many day services are well placed, with good leadership and governance and the restoration of staff redeployed to other settings at the peak of the crisis, to adapt and work to restoration of services.

4. The full implementation of New Directions is key to ensuring day services are person focussed and so adaptable to the changing needs of the person in this or any other circumstance.
5. As with other sectors financial assistance will be required for service adaptations to help overcome the challenges created by this health crisis. The Minister for Health must make available Covid- specific funding to allow for extra space/premises rental, the cleaning requirements to have safe premises, small works to premises and any additional support staff.

## Therapy inputs

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Most disability therapy services to adults and children have ceased during the Covid-19 period. Many of therapists have been redeployed to Covid-19 related work. This is having an impact on children and their development. Therapists have in many cases been redeployed into contact tracing and Covid-19 testing roles.

In two surveys (on education and adult day services) people indicated that they were receiving a very low level of support if any since Covid-19 had begun. A small cohort of people had received online or phone support which proved to be invaluable.

“Increase in behaviour that challenges during day service closure. Behavioural support by phone from the day service has been essential and very useful.”

When asked about the impact of this change, the most frequently voiced concerns were about the need for support to address anxiety, low mood and behaviours of concern arising from the constraints of the lockdown.

Other concerns expressed were about regression and a decline in mobility speech and language, and other physical skills in the absence of regular therapeutic support.

Parents of children also stated the absence of therapy supports during the Covid-19 period. Parents value these services greatly and noted the regression in their children in the absence of therapy supports. More than 53% of 1064 respondents said it would be hard for their child to return to school. To support children at home now and in their return to school parents stated the support of a speech and language therapist (43%), occupational therapist (40%) and psychologist (39%) would be invaluable. Many of these services can be delivered in a remote manner via telehealth.

The Covid-19 period has only exacerbated already very long waiting times for therapy supports and assessments. In the period to September 2019 only 10% of assessments of needs were completed within the statutory timeframes.<sup>4</sup> Many thousands of adults and children are seen by therapists in a relatively swift manner but many others languish on waiting lists for more than 12 months. Waiting longer than 12 months for therapy services there was 2830 for physiotherapy; 9296 for occupational therapy; 1035 for speech therapy and 2636 for psychology.<sup>5</sup>

These waiting times are not unexpected as therapy services have been operating with too few staff for many years. This has been most recently identified in a report by Working Group 1 of the Transforming Lives process of change in disability services. This report stated 300-400 additional staff were required.<sup>6</sup> There is also an unpublished report on the capacity of disability services to deal with current and future need.

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<sup>4</sup> Health services performance profile July – September 2019, HSE

<sup>5</sup> *ibid*

<sup>6</sup> Report on the future needs of disability services, Transforming Lives Working Group 1, 2018

## Recommendations on therapy inputs

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1. As the Covid-19 period is easing the redeployment of therapy staff into their 'normal' roles must be a priority. This will allow for the resumption of vital therapy supports.
2. Therapists must be trained in telehealth delivery and deliver services by remote means where possible to ensure the safety of staff and people who require the services.
3. Vital therapy services must be resumed as quickly as possible to address long waiting times that existed prior to the onset of Covid-19 and have no doubt been worsened during this period.
4. In the medium term, the Minister for Health must make funding available to lift therapy staffing to the levels set out in the report of Transforming Lives Working Group 1. Funding must be available to increase staff by 100 per year over 4 years.

## Mental health services

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With the publication of a new national mental health policy 'Sharing A Vision', it is timely that there is a focus on the provision of mental health supports for people with intellectual disabilities.

The previous national mental health policy '*A Vision for Change*' advocated for the development of 29 mental health teams for adults with ID nationally and 15 for children in 2007, and these teams would have 10 members each (290 team members in total for adults and 150 for children)<sup>7</sup>. However, Mental Health Intellectual Disability (MHID) services remain at 33% for Adults and 12% for children of the level that was envisaged in *A Vision for Change*.

Families and people with intellectual disabilities tell us that they feel invisible and poorly treated by the Mental Health services that they are struggling to access. Some areas have no MHID service or very limited service and 47.5% of adults with an Intellectual Disability over 40 have an emotional, nervous or psychiatric condition<sup>8</sup>. This is almost twice the rate of mental health problems of the general population.

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<sup>7</sup> A Vision for Change (2006)

<sup>8</sup> IDS, TILDA

The HSE's Mental Health Services has established a National MHID Programme, and a key part of the programme's work is the development and roll out of a targeted funding plan to establish a minimum basic service level. It is important that funding is immediately made available for this programme so that all people with an intellectual disability will have access to a basic minimum level of mental health service.

According to the United Nations, there is expected to be an increased need for mental health services worldwide as a result of Covid-19<sup>9</sup>. With a potential mental health crisis looming, it is vital that the MHID programme is funded and that there is widespread access to emergency mental health supports and investment in building support services in communities around the country.

## Recommendations on Mental health services

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1. Make adequate funding available for the National Mental Health Intellectual Disability (MHID) Programme
2. Ensure people with disabilities have equal access to mental health services and supports in their communities

## Residential services

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The Covid-19 period has been one of worry for the family members of people with intellectual disabilities living in residential services. Slightly more than 8300 people live in residential service and an additional 1500 or so people with a disability live in a nursing home who are under 65 years of age. Of the 8300 in a residential service up to 2900 live in larger settings of 10 or more people.<sup>10</sup> These 2900 people, along with the estimated 1500 in nursing homes have been at unnecessary added risk of catching Covid-19 due to their living arrangements.

As a result of the slow pace of de-congregation, people living in these settings have still not made the transition to living in community settings

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<sup>9</sup> United Nations (2020) Policy Brief: COVID-19 and the Need for Action on Mental Health

<sup>10</sup> <https://www.higanews.com/the-experiences-of-people-with-disabilities-in-congregated-settings/>

that are more personalised and offer a lesser risk of catching Covid-19. While people are moving, the progress is very slow and at current rates will take another 10 years at least.

Congregated settings are not compliant with Article 19 of the UNCRPD<sup>11</sup> which provides for people to have a right to live in community settings. Congregated settings are also less compliant with HIQA standards across a range of measures. HIQA, the HSE, the National Disability Authority, Genio and Inclusion Ireland have all reported on the positive impact that moving to community settings has on the lives of people with disabilities.

“Moving out of such arrangements into smaller or single occupancy accommodation has an overwhelmingly positive impact on residents’ lives. Residents who have made such transitions have told or showed us how important their bedrooms are to them and how they have personalised the rooms to represent their achievements and interests. Many residents living in the community highlighted that they had developed independent living skills or were being supported to engage in important everyday tasks such as cooking, cleaning and laundry. They also told us about how they are involved in their local communities and about their neighbours and new friends.”<sup>12</sup>

Despite many requests, there has not been regular reporting on the instances of Covid-19 cases and deaths in disability residential services. This has made people with disabilities and their families anxious as they can see the impact there has been on the nursing home sector. Sadly, at June 3<sup>rd</sup> 14 people had lost their lives to Covid-19 in disability services and around 300 people had displayed symptoms. However, the lack of regular, disaggregated information continues to be a worry.

People are also telling Inclusion Ireland that they have not been able to visit a family member or vice versa. This is causing quite an amount of distress. In addition, HIQA are not inspecting disability services in person to ensure residents rights are being upheld at this time. There are no outside visitors to disability services at present.

For the previous 10 years or so there has been very little additional provision of residential supports to people with disabilities. This has led to a great unmet need. The 2017 Report of the National Intellectual Disability Database Committee noted unmet need of 4544 in relation to residential services and supports required over the following 5 years. This

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<sup>11</sup> Article 19, UNCRPD

<sup>12</sup> Ibid

is currently not being planned for. Most people with intellectual disabilities live at home and of this cohort 4255 are over 35 living with aging parents. Of this 4255, 797 people over 55 with an intellectual disability live at home with aging parents<sup>13</sup> who are at least in their 70s and 80s.

In a recent report on housing, Inclusion Ireland found that people with intellectual disabilities experience a huge barrier in accessing housing through having no clear pathway to attaining support services. Many people report being unable to get access to a social housing home due to the unavailability of support services, while others who need supports in their home have no way of applying for these supports<sup>14</sup>.

## Recommendations on residential services

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1. Government must make funding available to the HSE to move the remaining people in congregated settings to homes in the community in line with Article 19 of the UNCRPD. This process should be ambitious and be completed over the life of the next Government.
2. A review must be carried out into the estimated 1500 people under the age of 65 who live in nursing homes at present. These people should be supported to live in ordinary homes in their communities in line with the UNCRPD.
3. The Government needs to make funds available to the HSE to provide supports to people to live independently with support in their own homes. This should include people with significant disabilities.
4. A priority review of the people with intellectual disabilities living at home with aging parents is required to assess and provide for their future living arrangements which must be in line with the UNCRPD. At present these people are not being planned for except for a small amount of 'emergency' places annually.

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<sup>13</sup> National Intellectual Disability Database 2017, HRB 2018.

<sup>14</sup> Inclusion Ireland (2019) Housing for People with Intellectual Disabilities, The lack of supports for Independent Living

## Conclusions

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The Covid-19 period has been difficult for all stakeholders. As a priority existing services need to be restored to previous levels to support people with disabilities. This must be done in a manner that is safe for people who use the service, their families and support staff.

The Government has many innovative policies on the delivery of disability services. The Covid-19 period has shown us that congregated provision of services places people at additional risk of contracting the disease. Now, as we emerge from the Covid-19 closures it is an opportune time to make progress on moving people out of institutions and congregated day services into community based, person focused services that support their individual needs.

This is what is needed, not just because it is in line with the UNCRPD but because it leads to more fulfilled lives for people with disabilities, so they can live self-determined lives and be more involved in their communities.