COVID-19 and Intellectual Disability

Supporting people with intellectual disabilities and their families

April 2020
About Inclusion Ireland

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

In March 2020 the World Health Organisation (WHO) declared the outbreak of the new Coronavirus, or COVID19, as a pandemic, due to its rapid spread around the globe.

Ireland, along with other countries around the world, is taking action and putting in place plans to curtail the COVID-19 virus. However, people with intellectual disabilities are a group at a significantly higher risk than others1.

As a result, it is important that additional considerations and supports are put in place for people with disabilities during this COVID-19 outbreak2, and that actions specific to this group in society are taken by Government, disability services, communities and people with disabilities themselves and their families.

These actions must be in line with the UNCRPD, and must support people with intellectual disabilities and their families through this emergency period, in line with Article 11 of the Convention which states that all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk are taken3.

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3 Article 11, UNCRPD
COVID-19 and Intellectual Disability

People with intellectual disabilities and their families need to be supported to access the health-care services and public health information they need in relation to the ongoing COVID-19 outbreak.

People with intellectual disabilities may be at greater risk of contracting COVID-19. Many are in a high-risk category as they may suffer from several health conditions, have low levels of literacy, and rely on others for support and care.

Other reasons people with intellectual disability are a high risk include:

- They have difficulty in taking part in social distancing due to additional support needs, or because of institutionalised settings and routines.
- There may be barriers to practicing good hygiene measures (due to inaccessible physical environments, or a lack of understanding of information related to good hygiene).
- People with sensory issues may need to touch objects to get information or for physical support.
- Public health information may be inaccessible.

People with intellectual disabilities may be at greater risk of developing more severe cases of COVID-19 if they are infected.

This can be due to:

- having underlying health conditions, such as those related to respiratory function, heart disease, diabetes
- being non-verbal or having limited ability to communicate the onset of or worsening of symptoms.
- facing many barriers in accessing healthcare.

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• the suspension or disruption of services that they would usually rely upon.

**What can people with intellectual disabilities and their families do?**

**Follow the HSE guidelines on COVID-19**

• Everyone should follow the basic hygiene guidelines during this period, such as washing your hands with warm water and soap, coughing and sneezing into a tissue, or if not into your elbow, frequently cleaning and disinfecting surfaces\(^5\). There are easy to read guidelines from Inclusion Ireland, HSE and others on following basic hygiene.\(^6\)

• Ensure you engage in social distancing and remain at home, unless you need to leave for essential reasons, such as shopping. Do not shake hands or make close contact with people. Reduce as many social interactions as possible and reduce the number of people you meet each day\(^7\).

• Ensure that assistive products are disinfected regularly. These could be wheelchairs, canes, walkers or other objects that are handled by you or others frequently\(^8\).

• Try and do your shopping online and get assistance from family members or support workers in doing so, in order to avoid unnecessary trips outdoors.

**Mental health awareness**

• Engage in activities and routines that might alleviate stress and anxiety. Some people with intellectual disabilities may not readily understand the reason for the sudden disruption to their normal routines and activities, and the need to be largely confined to their homes. This can lead to significant agitation, distress and a deterioration of mental health. This in turn may place significant additional stress on family members and carers who support them.

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\(^5\) HSE (2020) [https://www2.hse.ie/conditions/coronavirus/protect-yourself.html](https://www2.hse.ie/conditions/coronavirus/protect-yourself.html)

\(^6\) Inclusion Ireland [http://www.inclusionireland.ie/content/page/coronavirus](http://www.inclusionireland.ie/content/page/coronavirus)

\(^7\) HSE (2020) [https://www2.hse.ie/conditions/coronavirus/protect-yourself.html](https://www2.hse.ie/conditions/coronavirus/protect-yourself.html)

\(^8\) World Health Organization (2020). Disability considerations during the COVID-19 outbreak
In situations where a car trip can significantly alleviate this distress for a person with an intellectual disability, carers should be allowed to undertake these journeys, while “cocooning in the car”.

**What actions need to be done?**

**What can the Government do?**

1. **Accessible healthcare**
   - Ensure all public health information and communication is accessible for people with intellectual disabilities, in line with UNCRPD Article 9\(^9\). This includes having easy-to-read materials of all COVID-19 related information booklets and releases. If people with intellectual disabilities are to avoid contracting this virus, then they must be in a position to understand as much information as possible.

   - Work with disability organisations, advocacy organisations, disability service providers, and community groups where possible to disseminate public health information, but also to listen to what these groups are saying are the main issues affecting people with disabilities and their families.

2. **Providing services and supports**
   - Work with people with disabilities, Disabled Persons Organisations (DPO’s), disability representative organisations and others to identify the financial needs of people who may have lost their employment as a result of COVID-19.

   - Any large-scale financial stimulus packages introduced by the Government must be inclusive of people with intellectual disabilities, recognising that people with intellectual disabilities are 4 times at greater risk of experiencing poverty.\(^{10}\) This is supported by Article 5 of the UNCRPD which says that people with disabilities must not be discriminated against\(^{11}\).

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\(^9\) Article 9, UNCRPD
\(^{10}\) The Survey on Income and Living Conditions (SILC), 2018
\(^{11}\) Article 5, UNCRPD
• Identify and provide for the health and social care support needs of families where the primary caregiver who may need to self-isolate to protect their loved ones and is unavailable to support their family member with a disability.

• Provide care givers in the family home with Personal Protective Equipment (PPE) to reduce the risk of transmission between care givers and the people with disabilities they are caring for.

• Ensure that schools take measures to support children with disabilities while they are required to study and learn remotely.

• Ensure food and medicines supply to persons with disabilities living alone

• Provide income supports to people with disabilities and their care givers when they cannot work due to the need to joint isolate with their family member when ill.

• Provide a national phone number, where the latest information and guidance are read and explained for people with intellectual disability who cannot access the web page or may have problems reading and also to support families and carers of people with intellectual disability.

• Provide a national webpage with accessible information and resources for people with intellectual disability

• Allow people with autism (who may not comprehend the crisis) to access the streets with support during the COVID-19 restrictions, as not being allowed to go outside can be challenging and distressing. This has already been approved by the Spanish Health Ministry.\(^\text{12}\)

• Do not discriminate against persons with disabilities when deciding who has access to lifesaving treatment for COVID 19 (such as access to ventilators). This is supported by Article 25 of the UNCRPD on health, where it states that member States must not discriminate against people with disabilities in the provision of healthcare and provide the same standard as they would to

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\(^{12}\) Autism Spain (2020) \url{http://www.autismo.org.es/actualidad/articulo/el-ministerio-de-sanidad-dicta-una-instruccion-que-permite-las-personas-con}
others. Article 11 of the UNCRPD says that States must provide protections for people with disabilities when situations of risk arise within a country, and Article 10 says that States must protect the lives of people with disabilities, as all lives have equal value.

What can the HSE and service providers do?

1. Accessible healthcare

- Ensure that accessible information is always available to people with intellectual disabilities. This includes having information made available in easy-to-read or ‘social story’ formats in advance of COVID-19 testing appointments, and also during more long-term care provision in hospitals or at home. This is supported by Article 9 of the United Nations Convention on the Rights of Persons with a Disability (UNCRPD).

- Ensure that all clinical settings are completely accessible.

- Examine the possibility of delivering home-based consultations for people with intellectual disabilities who may be unable to travel or access external appointments. Also, for those may be more comfortable interacting with healthcare professionals in more familiar environments.

- Develop and maintain an “at risk” register, accessible through a helpline, for people with intellectual disabilities living independently, and for family members who are caring for people with intellectual disabilities at home. As part of this registration process, support and encourage the person with an intellectual disability, and/or their primary carer, to draft an emergency plan in the event of infection arising within their household.

- Provide healthcare workers and helpline operators with information booklets on intellectual disability so they are more aware of the potential health and social care needs of people.

13 Article 25, UNCRPD
14 Article 11, UNCRPD
15 Article 10, UNCRPD
• Provide extra supports for people with more complex needs and their families, in particular those people who are quarantined or isolated in their homes as a result of COVID-19.

2. Providing services and supports

• Ensure the increasing numbers of medical consultations that must be carried through telephone, skype and other computer modules are available and accessible to people with intellectual disability.

• Maintain phone access to psychological or behaviour management supports or helpline from the EIT/SAT services for children with intellectual disability and autism. The change to routines and increased time at home will be challenging.

• Ensure that quarantine for infected persons with disabilities is accessible, including physical accessibility and communication supports as needed. Mobility, communication or other aids of persons with disabilities should be taken by ambulance vehicles in cases where taken to hospital. Staff should be alerted to arrival of people with additional support needs and be knowledgeable about the needs of persons with disabilities.

• Ensure that, in the current circumstances with so much change and fluctuation, people with intellectual disabilities are treated with dignity and have their rights to consultation and privacy respected.

• Provide alternative separate local living accommodation in residential services with known staff members for residents diagnosed with COVID-19 who cannot, because of lack of capacity, voluntarily self-isolate. This is needed both for reasons of infection control, to protect other residents, and to respect the dignity of the person who is ill.

• Assess and support the situation of non-permanent residents who return to their families on a regular basis.

• Provide sufficient funding to sustain residential services through this emergency: to include overtime hours of work, suspension of holidays and leave in order to cover staff absences and maintenance of service and social care provision in the absence of
family and community visitors and volunteers, purchase of equipment and aids to prevent contagion etc.

- Ensure extra support activities for people in residential services who may not fully understand the crisis and are unable to cope with the new restrictions. Restrictions that have effectively blocked all social activities of the services.

- Put in place additional safeguarding measures and protections for people with intellectual disabilities to ensure they are not at further risk of abuse or neglect during this outbreak.

- Identify the potential for increased violence, abuse and neglect against people with intellectual disabilities because of social isolation and limits on people’s movements as a result of COVID-19. Try and promote proactive measures to mitigate these issues.

- Ensure effective communication between services and families where disability services are disrupted or suspended and the provision of some level of support in emergencies.

- Provide training to staff members working in disability services on infection control.

**What can communities do?**

1. **Public health measures**

   - It is vital that all members of the general public follow the public health measures introduced to halt the spread of the virus. These basic protection measures must be taken seriously, even by those who do not consider themselves high risk as you may pass the virus on to someone else.

2. **Public awareness**

   - Shop owners and shop chains should consider allocating specific times for people with disabilities to access their premises safely or provide a way for people to shop remotely online with delivery.
• It is important for members of the public to check in regularly with neighbours in their community who have a disability while respecting social distancing measures that are in place.

Conclusion

People with intellectual disabilities are a high-risk group and face a higher risk of contracting COVID-19 during this pandemic. They are also a group that face many barriers in accessing healthcare, and in accessing public health information.

For these reasons it is important that the State takes action to ensure people with intellectual disabilities are not discriminated against during this pandemic. This involves providing accessible information regarding the pandemic and related guidelines. It also involves ensuring that people with intellectual disabilities are supported to access healthcare and are given the supports to self-isolate and quarantine appropriately.

It is vital that people with intellectual disabilities and their families are supported throughout this difficult period by the Government, by the HSE, by healthcare service providers, and by their communities.

Resources:

For more information, you can read these other documents and easy-to-read resources below.

Inclusion Ireland

•  http://www.inclusionireland.ie/content/page/corona-virus

Health Service Executive (HSE)

•  https://www2.hse.ie/conditions/coronavirus/coronavirus.html

World Health Organisation (WHO)

•  https://www.who.int/emergencies/diseases/novel-coronavirus-2019
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