The rights of persons with disabilities in congregated settings within the COVID-19 emergency[[1]](#footnote-1)

April/May 2020

We recognise the extensive work and sincere commitment of the National Public Health Emergency Team (NPHET) in responding to the COVID-19 emergency. We appreciate the work of HSE Seclusion and Restraint working group to develop guidelines in relation to people with intellectual disabilities during the COVID-19 emergency. As this is an emerging situation it is important to use the limited information available to in the public spheres.

The purpose of this paper is to capture the critical information that may be relevant to Ireland at this time in relation to persons with disabilities residing in congregated settings.

This paper will outline the rights of persons with disabilities resident in congregated settings in Ireland under the UNCRPD. It will then look at reports and practices in other countries of how similar services are responding to the COVID-19 pandemic. It will make recommendations as to how to address core issues which have been identified by disability service providers in Ireland. This paper is focused on the operation of residential settings. We acknowledge that persons with disabilities living in the community will also experience significant barriers to the realization of their right to the highest attainable standards of health, the right to live independently and to be treated equally to non-disabled people. Adequate supports must be provided to persons with disabilities who receive support and care from family members.

# The World Health Organisation recognizes the increased risk of discrimination against persons with disabilities during the Coronavirus pandemic[[2]](#footnote-2). The UN Special Rapporteur on Disabilities has also criticized the lack of guidance regarding how persons with disabilities can remain safe during the pandemic[[3]](#footnote-3).

1. **United Nations Convention on the Rights of Persons with Disabilities**

Persons with disabilities have equal rights to non-disabled persons. The UNCRPD enshrines these rights and makes explicit the actions required of countries to realise these rights.

UNCRPD Article 5 enshrines the right to equality and non-discrimination. Article 5 requires that persons with disabilities be treated equally under the law. This will be of significant relevance where new legislation is being drafted in response to COVID-19. Further, it states that reasonable accommodation must be provided by states to ensure equality and that this does not amount to discrimination in itself.

Article 10 articulates the equal right to life and States must take measures to ensure effective enjoyment of this right on an equal basis with others. As healthcare services deal with the current challenges in restoring health and preventing death, it is important to recognize that all lives have equal value, especially in terms of resource allocations.

UNCRPD Article 11 obliges the state to ensure the safety of persons with disabilities in situations of risk, conflict, humanitarian emergencies or natural disasters. Although it is largely unexplored in a health pandemic context, it could also be applicable to the current situation. States therefore must ensure that laws, policies and measures, especially resource allocation measures, are carried out in a way that includes the protection of persons with disabilities from risk of disease and death.

Article 19 provides for the right to exercise choice and control over where and with whom to live, to participate in the community on an equal basis as other and to have access to any supports needed to enable them to live independently. As persons in congregated settings do not have control over where and with whom they live their ability to self-isolate and to protect their health is immediately at risk.

Article 25 enshrines the right to the highest attainable standards of health for persons with disabilities. Health facilities available to the general public must be equally available and accessible to persons with disabilities. This not only refers to physical infrastructure of healthcare settings, but information must be relayed in a way in which everyone can understand it. This might include preparing information in Easy to Read formats and facilitating a support person to attend appointments where this is the will and preference of the individual. Further, healthcare of the same quality must be provided in systems which are free or affordable to the individual and within reasonable distance of the individual’s community. Discriminatory practices on the basis of disability in the provision of healthcare is prohibited.

**UNCRPD rights issues in Ireland**: Persons with disabilities must have access to testing and treatment on an equal basis to everyone else in Ireland. Disability can never be a basis for discrimination in the provision of healthcare. Further, this crisis is causing disruption to general public services. Where a person with a disability is in receipt of health, personal or social services these must be reconfigured as far as practicable to ensure continuity of support and to avoid risk to health or life from non-COVID 19 related issues. This crisis has highlighted the dangers of congregated settings in protecting the health and lives of persons with disabilities in Ireland and the need to move towards independent living.

Advocacy is an extremely important service for persons with disabilities residing in congregated settings. Advocacy services can support an individual to express their will and preferences around where and with whom they live and the services they receive. The National Advocacy Service for Persons with Disabilities (NAS) in Ireland is a non-statutory agency, independent of service providers, who can fulfill this role. Advocacy typically involves in-person supports which have been severely hampered by the current crisis. NAS continue to provide a phone and on-line service and are engaging with their networks to assist in advocating for the rights of persons with disabilities during this time[[4]](#footnote-4).

The Health (Preservation and Protection and Other Emergency Measures in the Public Interest) Bill 2020 has been drafted in response to the COVID-19 crisis. The Bill has reached the penultimate stage of the drafting process and requires only to be signed into law by the President[[5]](#footnote-5). This legislation must be considered carefully as it has the potential to disproportionately impact persons within congregated settings. Section 11 of the Bill deals with detention and isolation of persons in certain circumstances. In summary this allows for:

* a medical officer to order the detention of an individual known to have, or suspected of having, COVID-19 and who has refused, or is unable to follow, instructions and as such is causing a risk to human life or public health. A medical officer is defined in the Health Act 1947 as ‘a chief medical officer, an assistant county medical officer for a county, an assistant city medical officer for a county borough or a district medical officer’.
* The duration of the detention is decided by the medical officer who has an obligation to review the situation and to ensure a medical examination is carried out within 14 days of the start of detention.
* The individual can request a review of their detention by a second medical officer to determine that they are not a source of infection and if this is found to be the case they can be released.
* The legislation **does not** provide for legal representation or advocacy to be made available to a detained individual.

This provision for detention is exceptional and must be used in a careful manner. Persons with disabilities who use diverse forms of communication and are not informed of the new social distancing and isolation regulations in a way that is appropriate for them could be subjected to detention under this law. All measures must be taken to ensure that information is available in various formats to give persons with disabilities the opportunity to adhere to the new regulations on an equal basis with others. The CDLP strongly recommends that an advocacy service be made available to individuals who are detained under this legislation to assist in the protection of the rights of the individual.

HIQA is the body responsible for monitoring health and safety within health and social care, including residential, settings. Inspections of settings has been suspended during the current crisis but the regulations and policies for maintaining and respecting the rights of service users apply equally now as ever. HIQA have written to designated centres to ask them to consider contingency plans for the current crisis, having due regard to staffing consideration, governance and management as well as infection prevention and control[[6]](#footnote-6). We welcome the recent announcement of the role for HIQA during this crisis. HIQA will undertake risk assessments as to which nursing homes require further support[[7]](#footnote-7). We request that this role is extended to people with disabilities in congregated settings as similar issues of infection control arise.

Alongside advocacy services, the implementation of HIQA standards will be crucial in respecting the rights of persons with disabilities in congregated settings.

**Fundamentally, persons with disabilities in congregated settings are not being given the opportunity to direct their lives in a manner which is consistent with the new social distancing and self-isolation requirements. Close contact with staff as well as fellow residents increases risks to contract COVID-19 which those not living in institutional settings can protect themselves against.**

**Evidence from other countries**

**Austria:** Incidents of infection of COVID-19 by staff and service users of a residential facility have already been reported[[8]](#footnote-8). The affected service users are quarantined within their residential unit. The member of staff is quarantined in their own home. Other service users have been removed to their family of origin where they are also under quarantine.

Non-government organisations are providing basic information about accessible health and social services for persons with disabilities and their families[[9]](#footnote-9).

**Spain:** While the country experiences severe curtailments of free movements in public, exceptions have been made to permit persons with disabilities and a support person to leave their residences for short periods of time[[10]](#footnote-10). This recognizes and ameliorates the aggravation of confinement on the wellbeing and behaviours of some persons with disabilities. Appropriate actions must be taken to prevent contracting the virus while outside of their place of residence. For those who are not eligible for the exceptions to confinement, the penalty for violating the policy ranges from a fine between €600 and €30,000 euro and imprisonment.

Harrowing reports from mainstream media indicate that there has been a total abandonment of care duties towards older people in some residential settings. Interventions by army personnel uncovered the breakdown of services in some Spanish settings[[11]](#footnote-11).

Official policy from the Spanish health service regarding the provision of residential services for persons with disabilities requires that families be kept up to date daily with the health and welfare of their family member and vice versa. The change of shifts of workers should be minimized and areas must be set up as isolation and treatment zones which is separate to the areas used by healthy residents. Staff must not cross between these zones.

**Portugal:** Guidelines have been issued by the Director General for Health indicate that residential settings for persons with disabilities are to remain open and maintain their levels of service provision, unless public health mandates a closure. It is permissible for new residents to be accepted in these times. This would be contrary to UNCRPD as efforts should be made to provide community based, rather than institutional supports. Services are responsible for the organization of their own personnel and should undertake stringent hygiene practices. Importantly residents of group settings do have the option of moving to community-based residences and they must be informed about the measures required to prevent spread of infection. If the individual has, is or suspected of having, COVID-19 they must remain in the institution.

Visitors are prohibited but technologies must be utilized to enable continued contact with family and friends as far as possible. Where staff or service users are suspected of being infected, they must be placed in quarantine and sanitization of areas they used in must be undertaken. Where supports are provided in the community appropriate actions to ascertain the safety of visiting people’s homes must be taken and all risk of infection reduced. More resources are being made available for personal protective equipment for staff. Personal assistance services should continue as far as possible if it is safe for both the recipient and the assistant[[12]](#footnote-12).

**UK:** The impact of austerity over the last decade has rendered social care services for persons with disabilities at a disadvantage facing into this crisis[[13]](#footnote-13). It should be noted that at the start of the COVID-19 crisis testing for COVID-19 did not occur within residential settings unless a resident was admitted to hospital. This resulted in the exclusion of residential settings from official data relating to the prevalence and impact of COVID-19[[14]](#footnote-14). Guidelines for residential care provision have been developed by the National Health Service and is being regularly updated based on best practices[[15]](#footnote-15). On a logistics issue, staff are requested to record capacity for bed vacancies and to use on-line communication tools such as Skype to communicate. Self-isolation is recommended for any staff concerned that they may have COVID-19. The wellbeing of residents should be considered when restrictions on visitors are being implemented. The same protocols as are used for influenza should be used. Isolation within a resident’s own room with en-suite facilities are recommended. New personal protective equipment must be used for each episode of care. Testing of residents can be organized if care homes have several cases at a time.

**European Disability Forum** have numerous resources in accessible formats providing information about the virus and measures to remain safe and healthy[[16]](#footnote-16). They have published demands for governments to ensure persons with disabilities are not forgotten during this crisis[[17]](#footnote-17).These include

* The need for accurate and accessible information in a timely manner delivered by both private and public providers, including digital communication devices and appropriate sign language.
* A gender inclusive approach, including the provision of reproductive health services and protection from violence. Appropriate protections for women with disabilities at work and equal compensation for loss of employment.
* Ethical guidelines developed during this time of crisis must not discriminate against persons with disabilities.
* The collection of data which correctly counts persons with disabilities within COVID-19 data and ensuring that regardless of nationality everyone should be appropriately provided for without discrimination.
* Consultation with persons with disabilities and their representative organisations.

1. **Learning for Irish context from other countries**

From Spain it is evident that persons with disabilities reside within nursing homes as well as disability specific group settings. There are a variety of on-going personal, social and health care needs to address as well as COVID-19 related health risks. Guidance and resources must be provided to all healthcare settings to ensure protocols are in place for continued care. To avoid the abandonment of vulnerable populations, the HSE must enforce the service level agreements with all disability and care service providers to ensure this does not occur in Ireland.

From Austria, concerns arise where there is not the option to quarantine in the family home due to elderly relatives or other household members with underlying conditions. There must be appropriate materials for residents explaining the current crisis, the rules around social distancing and the rationale for limitations on engaging with the community. A nationwide information service with Easy to Read documentation should be available in Ireland as part of public awareness campaign. See email re docs

The policies on social care services during the COVID-19 crisis are very clear in the U.K., Spain and Portugal. Similar guidance for Irish services must be made available as soon as possible. High standards of hygiene and careful planning of staff rosters and work environments will be of assistance in protecting the health of congregated setting residents.

There are efforts by European and International disability advocacy organisations to determine the availability of healthcare to persons with disabilities and to capture experiences so far. These are at an early stage but should be monitored in the future to keep abreast of any developments. These include the European Network on Independent Living[[18]](#footnote-18), Validity Foundation[[19]](#footnote-19) and the European Association of Service Providers for persons with Disabilities (EASPD)[[20]](#footnote-20). Data collection in Ireland is extremely important and it should be disaggregated to include disability. Deaths connected to COVID-19 even where the individual had not been tested before death must be recorded as such.

The guidance from Spain, Portugal and the UK emphasizes the importance of availability of PPE for healthcare and residential care staff should also be extended to staff and family members providing support and care to persons with disabilities in their own homes. Further, testing for COVID-19 should be available to all healthcare and support staff.

1. **Disability service concerns**

Further clarity is needed and the Department of Health must provide guidance for the protection of residents and staff within congregated settings. As of 30th March, there have been 22 clusters of COVID-19 outbreaks within nursing homes in Ireland and within four residential institutions[[21]](#footnote-21). It is unclear what the nature of these institutions are but this demonstrates the challenges in delivering safe residential services during this time. The following questions were posed by a consortium of representatives of disability service providers in Ireland. They are replicated here exactly as posed originally. This briefing paper offers suggestions based on the information available from other countries and international guidance to address the issues in a rights-based approach. \***The information should not be taken as healthcare advice.\***

1.      *Where COVID 19 is suspected in a person with an intellectual disability who is already very fearful of invasive procedures such as phlebotomy……..do we test them or do we  utilise clinical judgement and where there is a high level of clinical index of suspicion, isolate and treat as if the person had tested positive? This obviously has huge impact on contact tracing, other people living in the home, staff working in the home etc.*

UNCRPD Article 5 and 25 must be respected in these instances. Congregated settings often have medical and nursing staff on-site but this should not be considered as having the needs of the population met during this crisis. Ensure the individual is informed and consents to any health interventions. The UK guidance suggests providing care based on how the individual has received treatment in the past for contagious diseases, such as influenza. Due to the restrictions on availability of testing for the public, national policy is that if you suspect yourself to have COVID-19 to act as though this has been confirmed and to self-isolate and restrict the movement of household members[[22]](#footnote-22).

The guidance from Portugal, Spain and the UK about organising staff shifts to reduce risk of transfer of the virus, restricting the movements of staff to certain zones within services, maintaining high standards of hygiene and use of PPE are useful to protect both staff and service users.

2.      *Where a person with a disability requires hospitalisation – a guidance document for staff who may not be familiar with people with disabilities (adaptation of a Health Passport??)*

Under Article 25, all information which will enable an individual to receive the highest standard of healthcare must be made available to healthcare staff. Disability services should liaise with medical practitioners to ensure a handover of relevant information, including the communication tools or support devices used by the individual. Reasonable accommodation should be made where necessary to facilitate access to healthcare. A sample of a Health Passport from the HSE is available online[[23]](#footnote-23). Staff in healthcare settings must be made aware of this tool and engage with it.

3.      *Supporting people who may need to be tested and/or go into isolation who may then communicate their distress – how to support staff and people with disabilities in this situation.*

Again, Article 5 and 25 are most relevant to this situation. Where possible persons with disabilities should have access to a testing on an equal basis with others. The testing centre must be suitable for their needs – consent for testing must be ascertained, physical accessibility of the facility should be ensured, staff should be equipped and have experience in providing service to people with diverse needs. Time and resources should be available to support the individual to understand the process and what to expect beforehand. Public information must be fully accessible to people with diverse language and communication needs. As is promoted in the UK and Portugal, people in isolation should be supported to maintain contact with their family and friends using on-line communication tools such as Skype. Any updates about best practices should be provided to the individual in a manner which they can understand and are comfortable using. Inclusion Ireland has Easy to Read resources about hand hygiene and Coronavirus[[24]](#footnote-24). Services should also considering seeking training for their staff to administer the tests themselves. This will ensure familiarity with residents of congregated settings who are being tested for COVID-19.

1. **Conclusion**

There are real concerns for the health and safety of residents of congregated settings who have disabilities in Ireland. The emergency legislation allowing for detention of individuals deemed to be putting public health at risk must be used as a last resort when other interventions to support the individual to follow the new regulations have been exhausted.

It is important that accurate and disaggregated data about COVID-19 cases within congregated settings is collected.

This COVID-19 emergency is putting into sharp focus the egregious violations of fundamental rights which persons with disabilities are forced to tolerate in Ireland. Limited interaction with public amenities is usually a feature of daily life for persons with disabilities in congregated settings, however social distancing measures can further impact on their human rights under Articles 5, 11, 19 and 25 of the UNCRPD. While everyone in the country is being asked to curb their movements and undertake measures for social distancing, self-isolation and quarantine, these are much more difficult to realise in congregated settings. Alongside advocacy services, the implementation of HIQA standards will be crucial in respecting the rights of persons with disabilities in congregated settings. We request that HIQA’s new risk assessment role is extended to congregated settings.

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1. # This paper has been prepared by Dr. Áine Sperrin, post-doctoral researcher at the Centre for Disability Law and Policy, NUI Galway [-aine.sperrin@nuigalway.ie](mailto:-aine.sperrin@nuigalway.ie) The author is grateful to has assistance from local and European colleagues of the Centre for Disability Law and Policy for their input and feedback on content. Google Translate and Deepl.com have been used to translate documents which are not available in English. Due to the short turn-around in the preparation of this paper the author is restricted to considering countries where CDLP colleagues have responded to the request for support. These are Austria, Spain, Portugal and the UK. \*This paper does not constitute medical or healthcare advice and should not be relied upon as such. \*

   [↑](#footnote-ref-1)
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3. COVID-19: Who is protecting the people with disabilities? – UN rights expert

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4. Conversation with NAS Senior Staff member, 30th March 2020. [↑](#footnote-ref-4)
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19. Stephen Allen,Validity Foundation, validity.ngo [↑](#footnote-ref-19)
20. EASPD have set up a committed Facebook group to capture information from services and service users across Europe. <https://www.facebook.com/groups/1440520556130791/>.

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