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Title	Toolkit on best practice for health and social care professionals to respect the rights of persons with disabilities in public health emergencies
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Publication Date	2023
Publication Information	Flynn, Eilionóir, Doyle Guilloud, Suzanne, & Parker, April. (2023). Toolkit on best practice for health and social care professionals to respect the rights of persons with disabilities in public health emergencies. Galway: Centre for Disability Law And Policy, University of Galway. <a href="https://doi.org/10.13025/842e-gk07">https://doi.org/10.13025/842e-gk07</a>
Publisher	Centre For Disability Law And Policy, University of Galway
Link to publisher's version	<a href="https://doi.org/10.13025/842e-gk07">https://doi.org/10.13025/842e-gk07</a>
Item record	<a href="http://hdl.handle.net/10379/17774">http://hdl.handle.net/10379/17774</a>
DOI	<a href="http://dx.doi.org/10.13025/842e-gk07">http://dx.doi.org/10.13025/842e-gk07</a>

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Centre for Disability Law & Policy



# Toolkit on best practice for Health and Social Care Professionals to respect the rights of persons with disabilities in public health emergencies

## Introduction & purpose of toolkit

The Covid-19 pandemic put health and social care services under unprecedented strain. Before the development of effective vaccines, hospitals and intensive care units were pushed to the limit (and beyond) of their human and medical resources. Disability services were required to adapt to the continuously evolving pandemic-related rules and guidance. While it is to be acknowledged that the individuals working in these environments were working in extremely challenging conditions, and often engaged in innovative practice in order to try to preserve and protect the rights of persons with disabilities, there are clear lessons to be drawn from the Covid-19 period - both around the structuring of health and social care services, as well as practices which should be adopted in relation to people with disabilities in public health emergencies of this kind in the future.

This toolkit is intended for use as an advocacy tool by disabled persons' organisations (DPOs) in order to ensure that health and social care professionals (H&SC professionals) comply with their obligations under international human rights law in times of public health emergencies. It centres the experience of persons with disabilities, while also incorporating those of H&SC professionals and policymakers. It is primarily informed by the requirements of the [UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#).

It is complemented by a toolkit outlining the obligations of States with respect to the rights of persons with disabilities in times of public health emergencies, which can be found on the ResPoNCE project website.

## About the ResPoNCE project

### Aims

The ResPoNCE (Respecting Persons with disabilities' Needs and Rights in Crisis and Emergency) project sought to investigate the impact of the pandemic on persons with disabilities in Ireland, UK, Spain, France, Italy, Germany and Sweden. The research team sought to:

- Provide a critical analysis of the normative framework, including national legislation, policy and guidance issued by States throughout the lockdown and beyond, via desk research.
- Carry out key informant interviews with DPOs, health and social care professionals, policymakers and researchers to assess roles/responsibilities, aggravating /mitigating factors and the extent to which human rights obligations were met.
- Engage in other qualitative research – a questionnaire and focus groups - to explore and understand the lived experiences of persons with disabilities during the pandemic, including key topics such as healthcare, education and employment, independent living.
- Inform best practice for States and health and social care professionals to respect the rights of persons with disabilities in the event of another public health emergency, based on the UN Convention on the Rights of Persons with Disabilities (CRPD).

### Methods

The research team adopted a human-rights based methodology, guided by the principles of emancipatory research.<sup>1</sup> The participants for the study self-identified as having a disability/being disabled and were valued as experts by experience. Their involvement was facilitated indirectly through representative organisations (DPOs) and directly via a questionnaire (available in various formats). This was supplemented by the conducting of impairment/age specific focus groups to reach marginalised groups who may not otherwise have the chance to contribute e.g., children with disabilities, Deaf adults. The data was then analysed using reflexive thematic analysis.<sup>2</sup>

## Health and social Care professionals' human rights obligations towards people with disabilities in public health emergencies

### Non-discrimination

Equality and non-discrimination are two of the guiding principle of the CRPD and the obligations on States in this regard are set out clearly in Article 5 of the CRPD. Disability-based discrimination is defined in Article 2 as:

*... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;*

Article 25 of the CRPD addresses the right to health and recognises that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Persons with disabilities must be provided with 'the same range, quality and standard of free or affordable health care and programmes as provided to other persons'. Health professionals must 'provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent' by, amongst other things, 'raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care'.

Non-discrimination in the context of health and social care therefore has a number of aspects. Put at its most basic, it requires that people with disabilities be treated equally to others by H&SC professionals when they access health and social care services. This includes services related to their disability.

#### Resource allocation

##### *Triage/ethical decision-making*

Public health emergencies such as the Covid-19 pandemic have the potential to place extreme strain on medical resources. The most critical of these situations arises when someone requires intensive medical care where there may be a shortage of resources such as oxygen and ventilators. Another example during times of heightened strain on health services is when hospitals are at capacity and decisions are made to admit or not admit certain patients. In circumstances where the clinical resources available are unable to meet the needs of everyone requiring treatment, clinicians engage in a process of resource allocation or 'triage'. This involves the prioritisation of the provision of medical treatment based on factors such as the resources available, the severity of the condition of the person, as well as what their prognosis is.

In situations where decisions about the use of resources need to be made, the primary principle from a disability human rights perspective is that such decisions are made without reference to a person's disability/impairment. Article 25 of the CRPD contains a prohibition on the 'discriminatory denial of health care or health services or food and fluids on the basis of disability'.

However, the ResPoNCE project found that in some jurisdictions, triage decisions were made based on factors such as the existence of a disability or based on a person's age. These protocols usually came into effect at the height of the strain on healthcare services and shortages of resources. They were generally applied for short periods of time (often ceasing due to lobbying and complaints by disability rights organisations and other civil society stakeholders).

*... when the pandemic started, especially the first two weeks, people with disabilities weren't taken into account. ... even in the first two weeks ... protocols were approved that said that if there were any problems in a hospital, for example,*

*people who had disabilities would not be prioritised versus people who did not have disabilities in terms of Covid ...*

SPPR4

The Welsh government produced a [guidance document](#) on ethical values and principles for healthcare delivery framework which was one of the better examples of such guidance.

Similarly, decisions about whether a person should be transferred from their home or residential setting to hospital should be based on the same factors and ethical principles as for any other person. However, there is evidence that informal decision-making by institutional authorities resulted in some people not being appropriately transferred to hospital:

*... some people in nursing homes decided that they would not send these patients to the hospital ...*

FRHSC1

In some cases, the preference to avoid transferring someone to hospital was based on a perception that admission would not be of benefit to them:

*Our aim, and I think the aim of all the nursing homes is to try and keep our residents with us, try and keep them in the nursing home for as long as possible. Nobody wants a resident going to A&E [accident and emergency department] sitting on a trolley for hours and hours ending up in a ward where nobody knows them, unfamiliar surroundings...*

IRLHSC4

While wanting to avoid a distressing or frightening admission to hospital is understandable, decisions about whether to transfer a person should be based on both their wishes and clinical need, rather than on a substitute decision by staff (i.e. one which is made by someone else based on their assessment of the wishes of the other person, rather than by the person themselves), in accordance with the CRPD.

A means by which to ensure that the rights and lived experience of people with disabilities are included in the formulation of clinical ethics protocols is to ensure their active inclusion on decision-making bodies such as clinical ethics committees. This is consistent with the obligation under Article 4(3) of the CRPD for active involvement of persons with disabilities, through their representative organizations, in 'decision-making processes concerning issues relating to persons with disabilities'.

### *Vaccine prioritisation*

Many people with disabilities are at increased risk of mortality and morbidity in public health emergencies due to both pre-existing health conditions, as well as structural and environmental factors such as institutionalisation and reliance on others for support. However, in some cases, there was a failure to prioritise them for vaccination. Where prioritisation did happen, it was sometimes only focused on people with disabilities living in institutional settings, rather than the majority who live in the community.

*... there was... for it felt like a disturbingly large number of months a kind of 'Why aren't you listening to the fact that there's a group of people who clearly require vaccination? Or that the... the basis upon which you are proposing to prioritise older people, that basis applies just as much to these groups of people, because they've got specific issues, which means that if they catch Covid they're just in just as serious, if not more serious trouble than a person who's older.*

UKPR1

A model of resource allocation based on a human rights model of disability should ensure that persons with disabilities at greater risk in public health emergencies are high on the list of priority for vaccination. This should also extend to family members, carers and other supporters (e.g. personal assistants) of the person.

### *Personal Protective Equipment (PPE)*

An issue which arose for both clinicians and social care professionals during the Covid-19 pandemic was the availability of Personal Protective Equipment (PPE). This had particularly challenging implications when disability services and supports were provided in the homes of people with disabilities. This in-home support may have been in place before the public health emergency, or may have been a change that was made where public health measures meant that the person could not attend a service that they previously used outside their home. There was also a failure to provide PPE to personal assistants. In some cases, due to PPE shortages, people with disabilities had to either finance the purchase of the equipment themselves or make the decision to stop receiving support in the absence of adequate PPE, based on their own risk assessment.

### **Health and social care professionals should:**

- Ensure that resources allocation, triage and transfer decisions are non-discriminatory, and are not made on the basis of the existence of a disability.
- Recruit and actively include people with disabilities on clinical ethics committees.
- Prioritise people with disabilities in vaccination programmes.
- Prioritise the provision of PPE to people with disabilities, their families and supporters where they receive in-home services.

## Accessible healthcare and services

The obligation to ensure accessible healthcare during a public health emergency is contained not only in Article 9 of the CRPD, but also in Article 25, which guarantees the right to the enjoyment of the highest attainable standard of health for persons with disabilities. It also requires States to provide persons with disabilities with the same ‘range, quality and standard of free or affordable health care and programmes as provided to other persons’. Inaccessible healthcare may also go as far as violating Article 10, which guarantees that ‘every human being has the inherent right to life’ and requires States to ‘take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others’.

People with disabilities experienced instances of inaccessibility in accessing both general and Covid-related healthcare. This ranged from the inaccessibility of approaches to telehealth, to failures to recognise and respect the right to support such as personal assistants, as well as the inaccessibility of the communication of test results.

The [EU Accessibility Act](#) is a benchmark for achieving accessibility across a number of sectors. It is supported by the guidance on implementation contained in the [Design For All Standard](#).

Ireland’s Health Service Executive has created [National Guidelines on Accessible Health and Social Care Services](#) which address topics such as developing accessible health and social care services, developing disability competence, accessible services, communication, accessible information, and accessible buildings and facilities. The WHO has published a [Global Report on health equity for persons with disabilities](#) makes recommendations on how to ensure equal access to healthcare for persons with disabilities. The World Health Organization (Pacific Region) has created a [Disability-inclusive Health Services Toolkit](#) which sets out examples of good practice in the provision of healthcare to people with disabilities.

## Accessible Information

People with disabilities require accessible information in order to make informed decisions about their health and care. In its General [Comment on Article 9](#), the CRPD Committee makes specific mention of the importance of accessible information in the context of access to healthcare:

*All information and communication pertaining to the provision of health care should be accessible through sign language, Braille, accessible electronic formats, alternative script, and augmentative and alternative modes, means and formats of communication. (para. 40)*

The availability of accessible information regarding healthcare was also emphasised by the Committee in its later [General Comment on Equality and Non-Discrimination](#).

A Deaf person explained their experience of inaccessible information:

*So, with testing, you know, like the words or the phrases, I didn’t know what they meant. It was easier when they were translated. At first, I didn’t know. It is hard using that terminology. It wasn’t possible for the deaf community, I feel.*

IRD

Another research participant gave their opinion on the provision of accessible information:

*There should be resources for disabled people which give clear and internationally approved advice rather than waiting for the ... government to say "facemasks are good" or trying to deal with a 10 page testing kit leaflet that doesn't tell you where the tonsils are.*

MU UK 6

Accessible information can include Easy Read, Plain Language and braille. NHS England has produced [a guide and resources](#) on how to make health and social care information accessible. [Easy Health](#) is an online library of accessible health resources. SignHealth has a [database](#) of information on making health information accessible for Deaf people.

#### Accessible spaces

The need to provide testing and treatment facilities in public health emergencies can result in buildings and other infrastructure being used for the provision of these services which were not previously used for health or social care purposes. The inaccessibility created by past failures of universal design were heightened during the Covid-19 pandemic, where people with disabilities experienced difficulties in accessing testing and vaccination centres due to both the inaccessibility of the physical infrastructure, as well as ancillary elements such as transport:

*[The centres] usually are accessible but often what is forgotten is the information, the labelling where to go, how can I find myself around when I am blind, and so on. So, yeah. The big part is accessible but it's not perfect. Or for example, ... the centre is accessible and I received my vaccination when I come with my wheelchair but I have not a parking – I don't have a parking spot for my car and I need my car to be mobile.*

GRDPO1

The accessibility of a building or other space is supported and enhanced by the existence of appropriately trained staff. However, this was not always the case, as one Deaf person explained:

*... going into the testing centres, we nearly felt like robots. Obviously everybody had to wear masks, everyone had to have this and that, but it wasn't very personal. We felt like cattle being shoved in and we didn't know where we were going because obviously people were wearing masks and they were talking through their masks. I couldn't hear them, so I would nearly try looking at their visual cues and then... But it wasn't even... Like, we didn't know timewise how things were going to work and like, it was nearly like being in a foreign country is the way I can actually put it in that we didn't know where we were going, we didn't know what we were doing. Accessibility when you're in the testing centre was really, really poor.*

IRD



UNICEF's [Toolkit on Accessibility](#) contains general information on ensuring accessibility across premises and programmes, and addresses accessibility specifically in the context of emergencies.

**Health and social care professionals should:**

- Provide information on healthcare in accessible formats.
- Recognise the right of persons with disabilities to use support, such as personal assistance, in accessing healthcare.
- Design physical infrastructure related to healthcare provision based on the principles of universal design.

Telehealth

Telehealth - the provision of medical treatment remotely, e.g. online or by telephone, is a key aspect of providing medical care and treatment in circumstances where in-person consultations are not possible or deemed to be too high risk. In certain circumstances, telehealth can be a positive option for people with disabilities, providing additional options for access to care and treatment. However, one DPO noted how remote appointments with GPs created difficulties for people with intellectual disabilities:

*... no one's actually thinking about kind of having the digital platforms that are actually accessible to people with learning difficulties and people who value their independence and people who actually have a level of dignity they feel that they're losing their independence because over the COVID period they've been forced actually ... they're entitled to double appointment times which is 20 minutes, okay? But what we've found is that on phone calls or Zoom lengths, all you get is ten minutes, so you've lost your thinking time to actually answer the questions.*

UKDPO1

Members of the Deaf community experienced additional challenges in obtaining accessible healthcare as a result of the transition to telehealth:

*... it was very difficult when you were trying to even contact your GP because you'd have to book like a remote interpreting service and then your remote interpreting service, you only had a very limited amount of time to use the service. And so, if you were on a waiting list or on hold with the doctor, you'd end up using the whole remote interpreting service and then basically not having enough time for your actual appointment.*

IRD

The use of telehealth must be based on the principles of universal design, accessibility and reasonable accommodation. This therefore requires the provision of telehealth in a manner which takes account of varied means of communication and functioning. This may mean the provision of additional time for people who may have particular support needs, such as the presence of a personal assistant, or the provision of information in alternative and/or accessible formats. It may also mean that provision is made for in-person medical appointments where telehealth consultations cannot meet the needs of a person with a disability.

The World Health Organization and the International Telecommunication Union have developed a [global standard for accessibility of telehealth services](#). In addition, the National Disability Authority of Ireland has produced a [synthesis paper](#) on the effective implementation of telehealth in Ireland which has broader findings for other jurisdictions.

#### **Health and social care professionals should:**

- Embed accessibility in the provision of telehealth, include the provision of additional time for appointments where needed.
- Make provision for in-person appointments where telehealth arrangements do not meet the needs of a person with a disability.

#### **Respect for legal capacity**

##### **Informed consent**

The requirement for informed consent to medical treatment as set out in Article 25 of the CRPD finds its roots in Article 12, which recognises the equal legal personhood of people with disabilities and the consequent prohibition on denials of legal capacity (i.e. the right to decide and for that decision to be respected) based on assessments of mental capacity. It details a requirement for the provision of support to the person in order to respect the rights, will and preferences of the person. The CRPD Committee's [General Comment on Article 12](#) is clear that substitute decision-makers such as 'legal guardians' or family members, cannot provide consent to medical treatment on behalf of another person. The General Comment also states that:

*All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.*

(para. 41)

In some cases, great efforts were made to ensure that the informed consent of the person to medical treatment, testing and/or vaccination was obtained employing good practices such as providing accessible information, recognising the role of decision-making supporters that the person had chosen, as well as allowing the time and creating the environments which allowed the person to make their own decision.

However, in other cases, there were clear deficiencies in establishing whether true informed consent had been obtained. One person with a disability shared their experience:

*When I had the ... the second and first vaccine, I asked the nurse, I told her I take psychiatric medication, is there any contradiction with the vaccine, and she told me, oh well, we know so little, we don't really know anything. And then she proceeded to put the vaccine, to apply the vaccine on me, and I was left in a state of shock because I was doing this because of... I was taking the vaccine because of my job, working situation. And then I was left with this feeling that I didn't know what was going to happen ...*

SPPD

The provision of treatment and administration of vaccination programmes also revealed the problematic legacy of paternalism and substitute decision-making. One research participant explained:

*... you then realise the extent to which vast numbers of people had previously been entirely missing out on... well either missing out on the flu vaccine, because no one knew what to do, or were getting it in circumstances where if you actually looked at what was happening, it was like 'Can you tell me whether this vaccine was delivered on the basis of consent or on the basis of some weird 'We thought it was in your best interests, but we didn't ... or 'We just got your Mum to sign it.*

UKPR1

Reliance on the 'proxy' consent of legal guardians also occurred in some cases:

*... there was an effort to communicate clearly about who can consent or give authorisation for vaccination for people living in nursing homes if they have cognitive disability, if they are under guardianship, if the guardian is guardian for the person, for the welfare and so we could discover we knew that but we could discover that our system of guardianship is very, very, very complicated and you had 20 situations different but there was a general effort from guardianship sector for hospitals, for nursing homes to make clear from whom you should find consent or authorisation, that you have to inform the person first and ask her first and then to the guardian...*

FRHSC1

The New Zealand Office for Disability Issues produced [a Vaccination toolkit for disabled people](#) which includes guidance on ensuring informed consent. Another useful resource on ensuring informed consent or refusal is the [Process to support informed consent and will and preference](#) created by Ireland's Health Service Executive.

Further significant violations of informed consent during Covid-19 which arose in some jurisdictions were the placement of DNACPR ('do not attempt cardiopulmonary resuscitation') orders on the medical files of patients with disabilities without their consent. Such a practice is contrary to the equality and non-discrimination guarantees and the right to health contained in the CRPD. It also violates the right to life of persons with disabilities contained in Article 10 of the CRPD, which states that 'every human being has the inherent right to life' and that 'all necessary measures' should be taken 'to ensure its effective enjoyment by persons with disabilities on an equal basis with others'.

One research participant explained the impact of the non-consensual use of DNACPRs on the disability community:

*I think DNR, do not resuscitate is a huge fear – huge fear for a lot of people. That if somebody got COVID and ended up in hospital, that they wouldn't receive the same level of treatment as a non-disabled person. That was a huge fear, and that wasn't just in Ireland, that was cross-jurisdictional. I think there is that fear anyway, but in a pandemic situation – when you're hearing on the news that nursing homes and residential homes for disabled people were literally abandoned by staff in other countries. And they were abandoned by staff, and basically residents all died, because they'd literally just been left to die. When you're hearing that kind of stuff on the news, that does get inside your head, and it does really affect people. So, that heightens the fear. While there was nothing quite so overt here, fears weren't exactly realised here in that kind of way, it was just... sorry, this is a hard one.*

IRLDPO4

The [Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic](#) created by Ireland's Health Service Executive provides an example of an approach to resuscitation which expressly prohibits a difference in approach based on disability.

A core element of informed consent where there are concerns about future decision-making capacity, is the creation of systems and structures which both provide for and recognise forms of voluntary advance healthcare planning. This can either be by way of Advance Healthcare Directives, Power of Attorney, or other legal mechanism which allow the will and preferences of an individual to be clearly set out and adhered to.

#### **Health and social care professionals should:**

- Recognise and respect the right to legal capacity of all persons with disabilities, including their right to supported decision-making.
- Provide care and treatment based on informed consent in public health emergencies. This includes informed consent to decisions concerning resuscitation.

- Encourage the use of advance planning to give effect to the will and preferences of persons with disabilities in circumstances where there may be changes in their decision-making capacity.

## Respect for autonomy

### Maintenance of pre-existing supports/services

While many disability service providers made extensive efforts to maintain supports and services for people who used them before the pandemic, in many jurisdictions the focus appeared to be on prioritising the maintenance of services for people in residential/congregated settings, as opposed to those who received services in the community. Redeployment of staff to pandemic-related roles and concerns about disease transmission resulted in the reduction or complete cessation of day and respite services.

*I think in the early days of the pandemic one of the big challenges as well for people who have disabilities was the provision of care, personal care. So, I mean literally overnight it would be your carers aren't coming in because of COVID. It took a while to get to grips with how the system might work in terms of carers going into people's houses, there was a huge issue here around the appropriate provision of PPE, around all those issues which took a while to resolve and as a result, I think people got a poorer level of service and very often families were expected to step in. And I think that caused a huge amount of stress and anxiety for families. And people took on informal caring roles who hadn't been doing that before and there wasn't a huge degree of support for them.*

UKPR2

Even when services were resumed, they did not return to their pre-pandemic levels:

*... right across the board, services were scaled back – they had to be scaled back because of numbers. So, there's going to be a loss there. So, if a person had a five-day service, it was... once people started to come back into services, it was scaled right back to maybe two days a week. So, in terms of compensation, there wasn't, people lost out as a result of... and that's right across the board, not just for people with disabilities, but for all services, things were completely scaled back. And then some services, they didn't get back up and running at all.*

IRLHSC1

In some cases, efforts were made to maintain some level of support online or via telephone contact, but this was generally found to be insufficient by the service users themselves:

*My own support stopped during lockdown but my staff phoned me to see how I am doing; I was only getting support from my mum and dad. Now I have some support*

*back but the staff from the centre I used to go to have not been in touch to say if they are reopening and if I will have my place back.*

UKDPO4

Worryingly, the reduction in support has been used as a justification by health and social care authorities to not restore services to their pre-pandemic levels. One DPO explained their concerns:

*... many people with a learning disability have had their support reduced or stopped completely during the pandemic. For years we have had to live through local authorities trying to save money by reducing and stopping support. Support is often only provided in crisis situations or where someone is considered to have very high needs. We are worried that reductions or stopping of support maybe used as a way of saving money even now that other restrictions have been lifted members have since been told that if they managed without support during the pandemic, they can manage without it in the future but they don't understand that many of us did not manage, we struggled by.*

UKDPO4

People with disabilities also experienced delays or cessation in access to services such as repairs of assistive devices, and access to rehabilitation services.

**Health and social care professionals should:**

- In public health emergencies, maintain a minimum level of core staff who continue to provide in-person disability services, and are provided with adequate and appropriate PPE.
- Where it is necessary to temporarily deliver services remotely, ensure that this is accessible for the person concerned, bearing in mind the high levels of digital exclusion experienced by people with disabilities.
- Restore support and service levels to their pre-emergency levels as a priority.

**Prohibition on increased institutionalisation and/or deprivation of liberty**

While health and social care professionals do not usually have a direct role in the formulation of deinstitutionalisation policies, they do still have the power to control the administration of institutions. These include hospitals, nursing homes, and psychiatric facilities.

The increased risk posed by institutional settings during the pandemic should provide even further rationale to support persons with disabilities to transition into life in the community. As one DPO for people with intellectual disabilities explained:

*Many people with a learning disability still have little or no choice in where we live or who we live with. Sharing homes and flats with people we don't know or haven't*

*chosen to live with happens often. There are still people with a learning disability that have to call hospital, a home. People with a learning disability are sometimes told that being in a hospital or a group home or a care home is the only place available where it is the safest place for them to be. We do not agree and history tells us that people are more vulnerable inside these institutions. During the pandemic we have also learned how some care homes have experienced high levels of infection from coronavirus, at the start of the pandemic they were not given the same priority for PPE and testing as hospitals.*

UKDPO4

There were increased restrictions on the rights to liberty and privacy and family life of people with disabilities in institutions due to visiting bans/restrictions. In some cases, there was also a cessation of discharges of persons with disabilities from those settings.

*Elderly homes, there was a national approach, they were not allowed to have visitors. And these other people with disabilities, it was a little bit depending which kind of institution it is, if they are ill, if they are a risk group or something. But as far as I am concerned, I think it was so that most of them were closed for visitors, it was not possible. Which was a big issue, of course. Especially if you had a disability. Many people with disabilities might have even more need of having people around ...*

SWHSC1

*People interpreted the texts differently and sometimes didn't read thoroughly or chose to ignore some elements, such as the government at one point said no more visits in retirement homes or special needs centres, and so the centres profited of this and decided that there were absolutely no visits. Whereas, if they had read between the lines, then visits were accepted, but it just made life easier for them to refuse all visits, and so this impacted the people who suffered even more isolation from their families.*

FRDPO1

A particularly shocking restriction on visits to children with psychosocial disabilities in a psychiatric unit was mentioned by one research participant:

*... a children's ward had prevented relatives from coming for 11 weeks. ... So, parents weren't seeing their children for 11 weeks because of an infection risk.*

UKHSC4

In other cases, there were reports of blanket restrictions on liberty without any lawful basis:

*... we all know [of people] who are living in a nursing home or residential home, that despite the fact that when doors were opened to everyone, despite this, some nursing homes or residential homes where people with intellectual disabilities live did not let them go out. There are people with disabilities who have been locked down much longer because they made this decision unilaterally ...*

SPID

In its [Guidelines on deinstitutionalization](#), the CRPD Committee is clear that '[i]nstitutionalization must never be considered a form of protection of persons with disabilities' and that '[t]he exercise of the rights under article 19 of the Convention [the right to live independently and be included in the community] cannot be suspended in situations of emergency, including in public health emergencies'. In public health emergencies, institutional settings cannot, therefore, use arguments based on 'protection' or 'risk' to justify pausing discharges or restricting visits in excess of the rules and restrictions which apply to other members of the public.

#### **Health and social care professionals should:**

- Prioritise and accelerate processes of deinstitutionalisation during public health emergencies, in consultation with representative organisations of persons with disabilities, and using the Guidelines on deinstitutionalization as a policy framework.
- Refrain from reducing or ceasing discharges from institutional settings based on public health emergencies.
- Ensure that visits are maintained in accordance with public health guidance and including considerations of reasonable accommodation.

#### Examples of good practice

##### Vaccine prioritisation

*... vaccination has been organised in several phases, four phases actually, and connected to vulnerability. So, risk group and people working with risk group. So, phase one was elderly people and staff working with them, and people who live with them. Phase two was people with specific illnesses and people who live in homes for people with intellectual disabilities, or... and people with disability assistant and their staff. So that's where the disability group came into this, except that elderly people also have disabilities obviously. And then phase three were people above 18 in risk groups and also people who have difficulties understanding and following recommendations due to an intellectual disability for example. And then phase four is the rest, from older and younger and younger. And then women under 65 we're not giving the Astra vaccine.*

SWPR1



## Testing

*I went for a test because I thought I had the COVID and [00:24:38.0] test and it was over in, I think it was over in Swords or something I'd to go to and I actually had no transport to get there. So, [00:24:49.7] person from the place, a doctor, to pick me up to bring me over and then they brought me home again. Lucky enough I hadn't got it, thank God. But they were very helpful if you ring up and asked them. If you explain that you haven't got much mobility, they'll send someone out and a lot of people were getting [00:25:08.9] that couldn't get out at all, they were bedridden or something. They couldn't get out at all. They would actually come out and do the test which I found that was very helpful.*

IRID

## Access to healthcare

*... we developed a bespoke ... neurodiverse clinic where there were all kinds of things done. They were given a specific part ... of the vaccination centre was just for neurodiverse children. They were... there were beanbags, there were... the beds were down on the ground, if they wanted a bed to lie down on, there were toys, there were... it was specifically arranged so that the exit door was right next to where this was, so that if they needed to get out and run around for a while, they could do that, if they got scared, if they got anxious. There was way more time allowed per vaccination when they were scheduling them, so that a person could come in, they could make an attempt, if he just freaked out and couldn't do it, he could go off, he go out, run around outside for a little bit, the team would go out to him, sit him on a... he could sit on a bouncy ball, one of those gym balls, if that was where he was more comfortable, and he'd be vaccinated there.*

IRLHSC5