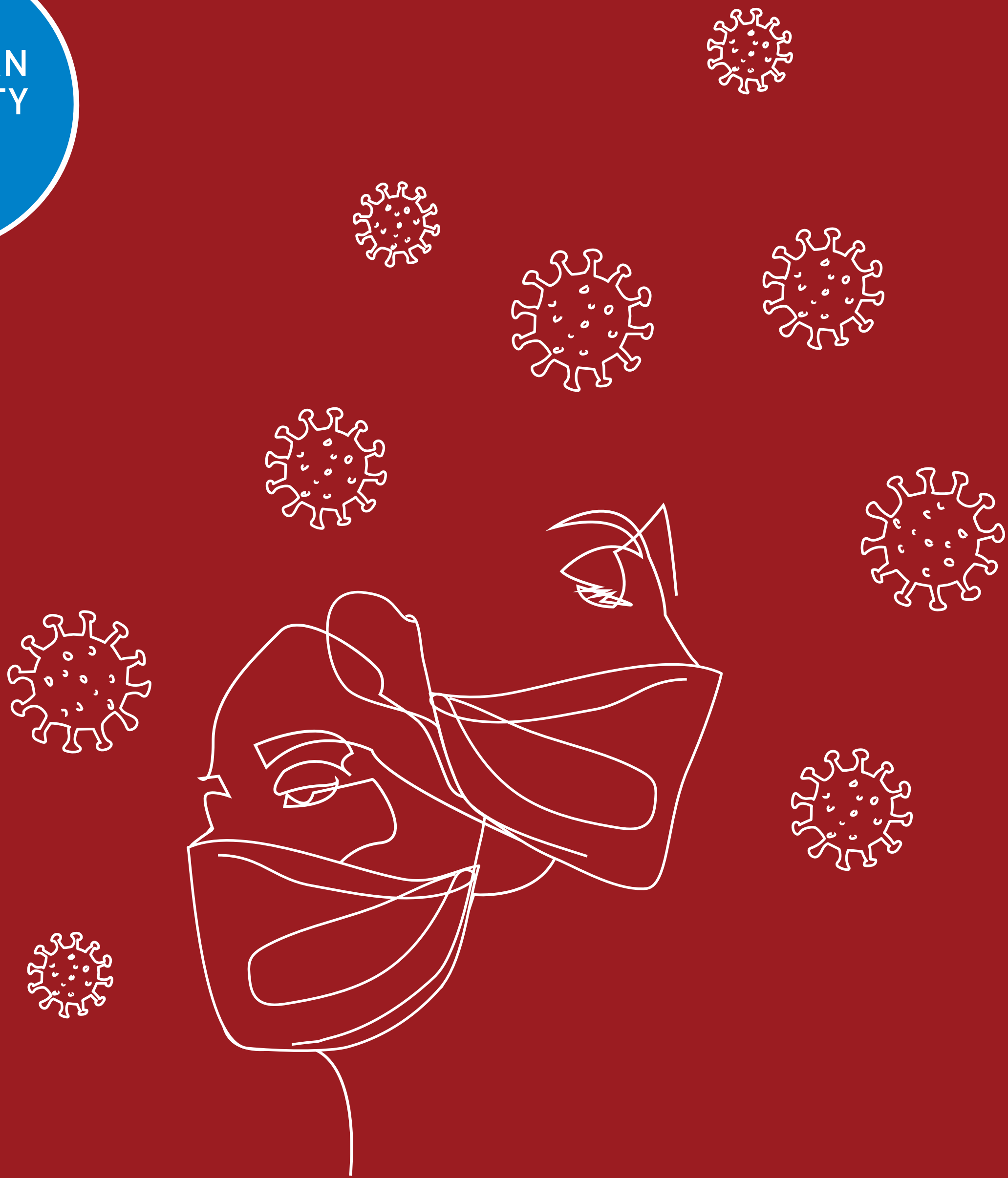

Impact of COVID-19 on persons with disabilities:

European Leaders must act now

Extract from the Human Rights Report 2020

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This paper gives an overview of the impact of the COVID-19 pandemic on persons with disabilities in Europe and draws specific recommendations for the EU and European countries. It is based on the EDF Human Rights Report on COVID-19 that will be published in early 2021.

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A word from the president

"NOTHING ABOUT US WITHOUT US"

These words are our motto. It has not been the reality during COVID-19. Everything about COVID-19 affected us. The pandemic has exposed the consequences of years, decades, centuries of inequalities, discrimination, and seclusion faced by persons with disabilities, women with disabilities, children with disabilities.

No one was prepared for a pandemic. Governments were not prepared and reacted slowly to protect our lives and rights. The Disability movement was not prepared and reacted bravely and strongly.

This report is the beginning of our work, not the end. It shows how most governments failed their legal obligations towards persons with disabilities. It shows what happened to persons with disabilities in the different phases of the pandemic. It shows how the immediate and strong advocacy led by persons with disabilities and their representative organisations has compelled many governments to take actions to ensure our rights.

Enough was enough. We told government that they needed to communicate in a way accessible to all. We told government we needed to be included in the immediate response. We told governments that they could not segregate us anymore. We told it all and loud.

This is the goal of this report: it aims to clearly show how failure to include us led to unprecedented human rights violations and how the disability movement was able to quickly and fearlessly lead to policy changes.

One thing is clear: some governments heard us and acted,

some did not. In all countries, at all levels, a lot of work still need to be done. This report is dedicated to all persons with disabilities that died of COVID-19, often alone and unsupported, and to persons with disabilities and their families, and support networks, who still today are disproportionately affected by the COVID-19 pandemic.

We will not stop until all our brothers and sisters are included in society. Until all institutions are closed and support to live in the community provided. We will not stop until all of us can thrive and know that, when the next crisis arrives, our lives will not be considered as less valuable.

This report aims to be a source of inspiration for 2021.

It provides recommendations to the EU, to national governments and to ourselves, in the disability movement. We can do better and must all act now to ensure an inclusive COVID-19 recovery. Let's build back a better Europe.

Yannis Vasdakastanis
EDF President

About EDF

The European Disability Forum is an independent non-governmental organisation (NGO) that defends the interests of over 100 million persons with disabilities in Europe. EDF is a unique platform which brings together representative organizations of persons with disabilities from across Europe.

We are run by persons with disabilities and their families. We are a strong united voice.

Our mission is to promote equal opportunities for, and human rights of, persons with disabilities in Europe.

Context

Over 100 million persons with disabilities live in the European Union and a much higher number if we consider the European countries outside the Union itself. Before COVID-19 hit Europe, an unacceptable percentage of persons with disabilities were living in precarious situations at the margin of society, with more than 28% of all persons with disabilities currently living in poverty and experiencing social exclusion in 2018[1]. Only 20.7% of women with disabilities and 28.6% of men with disabilities were in full time employment in 2019[2]. The factors which are leading to this situation of discrimination, poverty, and social exclusion have been documented in previous human rights reports published by EDF[3].

The pandemic exposed the underlying inequalities and discriminatory practices faced by persons with disabilities in Europe and worldwide[4]. In addition, several other societal factors have increased the risk of persons with disabilities being infected, discriminated when accessing treatment, and dying from COVID-19, including institutionalisation and segregation, lack of accessibility, and exclusion of persons with disabilities and their organisations from decision-making.

Factors increasing the risk of persons with disabilities to COVID-19 infection

Due to the variety of factors described below, persons with disabilities have been more likely to be infected by the coronavirus, develop serious illness, and die.

Medical conditions and unmet needs for healthcare

Pre-existing medical conditions have been considered high-risk factors for COVID-19. While some persons with disabilities have underlying health conditions associated with their disability, others do not. However, it must be noted that persons with disabilities are more at risk of ill-health due to unmet needs for healthcare and a lower standard of living[5]. Overall, persons with disabilities are more susceptible to secondary conditions and co-morbidity, such as lung problems, diabetes, heart diseases and obesity, which can worsen the outcome of COVID-19 infection[6].

Barriers in access to healthcare

Due to lack of accessibility and discrimination, persons with disabilities have greater difficulties in accessing healthcare and life-saving operations, especially during a pandemic such as COVID-19. In some countries, persons with disabilities are directly discriminated against through triage protocols or indirectly due to de-prioritisation[7]. This is often due to discriminatory criteria such as age, or assumptions about quality or value of life based on disability[8]. Even in countries where this might not be the case, persons with disabilities may wait longer or not seek treatment due to the fear of not being treated appropriately[9].

Older age

The World Health Organisation considers older age a risk factor for COVID-19[10]. Worldwide, an estimated 46% of people aged 60 years and over are persons with disabilities[11]. Therefore, there is a high percentage of older people who have always lived with disability or acquired it at a later stage in their life.

Institutionalisation

Persons with disabilities living in institutions are more likely to be infected by COVID-19 and have higher rates of mortality. Persons with disabilities, including older people, represent the majority of institutionalised people globally[12]. Although there is no official data on the number of people living in institutions in the EU, we estimate that at least 1 million persons with disabilities are living in such settings[13].

People living in institutions have limited access to COVID-19-related information, testing, and healthcare. They also face difficulties in implementing hygiene and protection measures[14]. Children and young people with disabilities living in institutions were also at risk when governments took no measure to protect their health and safety[15].

Data available indicates that people in institutional settings are facing the highest rates of infection and mortality from COVID-19[16]. In Slovenia, for instance, 81% of the COVID-19 deaths were among care home residents[17].

Barriers in implementing hygiene and protection measures

Persons with disabilities often face barriers in implementing the hygiene and protection measures put in place by governments. For instance, they may have difficulties washing their hands often or respect social distancing due to a variety of factors: lack of accessibility of water, sanitation, and hygiene facilities; a reliance on physical contact to get support; inaccessible public health information; or being placed in institutional settings which are often overcrowded and lacking sanitary facilities[18]. Some persons with disabilities may also find it difficult to wear face masks.

Belonging to other disadvantaged groups

Other facets of the identities of persons with disabilities, such as their belonging to other disadvantaged groups, put them at greater risk of COVID-19 infection and impact. For instance, prior to the pandemic women with disabilities were already three times more likely to have unmet needs for healthcare[19]. The United Nations denounced the 'appalling impact' of COVID-19 on racial and ethnic minorities due to a range of factors including discrimination, unequal access to healthcare, and poverty. Other groups such as LGBTI+ people, refugees and asylum seekers with disabilities, homeless persons, and persons with disabilities in prison have been facing additional discrimination and risks of infection.

Overview of the pandemic and European response

On 31 December 2019, the Wuhan Municipal Health Commission in China reported a cluster of cases of pneumonia in Wuhan in Hubei Province. A coronavirus was eventually identified. Less than a month later, on January 24th, the three first cases were confirmed in Europe.

Italy was the first European country to declare a state of emergency and to impose a general lockdown on the population due to the pandemic. Mid-March 2020, several European countries followed.

During the first phase of the pandemic, out of 32 European countries (EU countries plus Iceland, Liechtenstein, Norway, Switzerland, and the UK), 17 countries declared a state of emergency[20] and 19 countries went into lockdown. Some countries did not go into full lockdown but had some restrictions in place, such as closure of schools and non-essential shops. This includes Croatia, Denmark, Germany, Hungary, Iceland, Liechtenstein, Luxembourg, Malta, Slovakia and Sweden[21].

The European Union, through the Council of the EU representing Member States and the European Commission, took specific steps to address the pandemic.

An analysis of the response to the pandemic illustrates the lack of consideration of disability rights and states' obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[22]: from preparedness to recovery, persons with disabilities were left behind and had to strongly advocate for their rights. A majority of governments failed to involve persons with disabilities and their representative organisations in decision-making prior and during the pandemic. This led to widespread and severe human rights violations under the CRPD and the deaths of persons with disabilities across Europe. Societies that were not inclusive could not ensure an inclusive response to the pandemic.

Preparedness

Preparedness planning for a public health emergency ensures the availability of capacities and capabilities to detect, notify, respond to, and recover from an emergency before the emergency arises.

Despite legislation and guidelines on the topic, EU and European countries were not fully prepared for a pandemic and not prepared for a disability-inclusive response to COVID-19. Organisations representing persons with disabilities were not consulted on preparedness, disability support services were not on the list of essential services, and there was no specific attention towards older people and people in institutional and closed settings.

For example, the European Centre of Disease Prevention and Control's operational checklist for health emergency preparedness does not include any mention of persons with disabilities or consultation/involvement of civil society. It is a glaring gap to prepare for or respond to a pandemic without consulting those most affected.

Beginning of the pandemic in Europe

The first stage of addressing a pandemic involves urgent communication and adoption of emergency policies. The CRPD obliges countries to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk and humanitarian emergencies (article 11), to provide accessible information and communication (articles 9 and 21), involve persons with disabilities through their representative organisations in all matters that concern them (article 4.3), and ensure equality (article 5).

This is what the EU and the European countries failed to do from the beginning of the pandemic. The first response was slow and reflected the stereotypes about and exclusion of persons with disabilities. Assuming that the virus was mostly dangerous for "the most vulnerable", including people with lowered immune systems, older people, and persons with disabilities, many countries started

taking measures only once a higher number of cases and deaths affecting people outside these groups was reached.

Communications about the virus and measures taken were not accessible to all people with disabilities. This particularly affected Deaf, hard of hearing and Deaf-blind people who did not have access to information in national and international signs. It also affected people with intellectual disabilities and autistic people because of the lack of information in plain language and Easy to Understand formats.

The EU organised its first press conference on COVID-19 on 29th February. This was followed by several other press conferences, with no captioning or sign language interpretation. The first information translated into international sign was a video message of the President of the European Commission on guidelines to ensure the free movement of critical workers on 30th March.

In most countries, organisations of persons with disabilities were not proactively consulted by their governments.

Lockdown and/or restriction measures

Lockdown, state of emergency, and temporary restrictions meant that, for several months, the lives of everyone in Europe changed drastically. During the first lockdown and restriction measures adopted in March/April 2020, schools and non-essential shops were closed in a wide majority of European countries. Gatherings were banned in 26 countries. In 6 countries gatherings were allowed, but with numbers limited to a maximum of between 10[23] to 1000 people[24]. Almost all countries adopted travel bans, closed their borders, or installed border controls of some sorts.

In October 2020, new restrictions and partial lockdowns were announced in several countries following a “second wave” of COVID-19 cases.

Governments have mostly failed to adopt restrictions and lockdown measures that complied with the rights of persons

with disabilities. They have also failed to prevent human rights violations from occurring. They include issues regarding access to education, employment and healthcare services, disability support services, gender-based and domestic violence, involuntary treatment in psychiatry, and human rights violations in institutions.

Home schooling and home working

In most countries, people with disabilities had to stay at home, with no access to their personal assistant and no support. Children and students with disabilities had to adapt quickly to online education, requiring access to a computer and internet (which may not be available and accessible to all of them) and often without adequate support (class assistant, interpreter). Workers with disabilities also faced the same issues with home working policies that were not accessible and where reasonable accommodation was not available. When remote working was not possible, workers with disabilities have been laid off and faced sudden unemployment with no support. This situation was aggravated by the extra disability-related costs people with disabilities already face (extra costs including accessible housing, transport, assistance, technical aids and equipment etc.)[25].

Persons with disabilities have, on average, less access to the internet and digital tools[26]. This period of accelerated digitalisation has created further exclusion and increases digital inequality[27]. Many parents with disabilities and parents of children with disabilities did not receive support during the lockdown, and had to be available 24/7 for their child, often home-schooling them with no assistance. This particularly affected women, who are more likely to bear the caring responsibilities[28], or to be the sole carer of one or several children[29] or relatives with disabilities.

Gender-based and domestic violence

Data available shows that gender-based and domestic violence has spiked during lockdowns. For example, in France, reports of

domestic violence have increased by 32% during the lockdown[30] and in Cyprus, helplines have received a 30% increase in calls[31]. Although we do not know the proportion of women and girls with disabilities that have been victims of violence during the pandemic, the UN Office of the High Commissioner for Human Rights (OHCHR) has reported that, globally, women with disabilities, although likely facing higher numbers of domestic violence, are reporting less. This lower reporting rate can be due to a variety of challenges that pre-existed COVID-19, such as a lack of awareness, but also inaccessible helplines, reporting mechanisms, and overall support services for victims including shelters.

Isolation and human rights violations in closed settings

Isolation, violence, abuse, and lack of support particularly affected persons with disabilities living in closed settings, including children, young, and older persons with disabilities. In particular, those in institutions in psychiatric hospitals, in prisons, and in refugee camps paid the highest price of the pandemic. They were more at risk of being affected by the virus during the lockdown period, and the least likely to receive healthcare. They were also completely isolated, feeling locked-up with no authorisation to receive visits and no information on why they were not allowed to leave their closed settings. Children with disabilities, in particular children with intellectual or psychosocial disabilities, and children on the autism spectrum, were strongly impacted by isolation and staying at home orders, when no exception was made by governments[32].

In most of the countries, the majority of the deaths occurred in institutions and older people's residences. This is due to a range of factors including a very limited response from governments, lack of personal protective equipment, lack of testing for staff and

residents, and inadequate access to healthcare.

People with disabilities have paid the price with their lives. There has also been an extreme impact on mental health. Reasons include inadequate or inaccessible information on the situation, forced isolation with no devices to communicate with their support network, and an overall absence of support. There has also been a higher number of cases of involuntary placement and treatment in psychiatric hospitals during the lockdown.

Discrimination in accessing healthcare services

Persons with disabilities living in the community faced similar barriers in accessing healthcare services. Either triage guidelines denied access to healthcare for persons on the basis of their disabilities, or, in practice, they were refused access or deprioritised in hospitals, which have been overwhelmed by the crisis. These examples of not being able to access medical care also create a situation of mistrust in the healthcare system resulting in persons with disabilities waiting longer to go or deciding to not go to their doctors or to hospitals in order to avoid refusal.

Lack of support in the community

Additionally, persons with disabilities living in the community, either on their own or with family, peers, and/or friends had to face a sudden break down in community supports, ambulatory services, personal assistance, and assistive technology due the inadequate response of governments to the pandemic. When family members, relatives, peers, assistants, carers, and staff members of service providers had to go into quarantine, or got ill and could not be replaced, persons with disabilities found themselves without any support. Even access to medicine and adequate nutrition was difficult or even impossible due to isolated living conditions, loss of income, and lack of financial support[33].

Lifting of lockdown and restrictions

From the end of April to June, countries started to lift their lockdowns and some restriction measures. While shops and some schools started to re-open, some restrictions and measures still applied. In most European countries, wearing a face mask became mandatory on public transport, in shops, or in all public spaces, and some rules of social distancing were enforced. In October, depending on the number of new cases, countries and regions reintroduced partial or total lockdowns. Once again, persons with disabilities were mostly left behind. Either they faced longer confinement measures, still without specific support, or started to disproportionately feel the socio-economic impact of the pandemic.

On 15th April, a joint EU Roadmap to lifting coronavirus measures recommended that the "most vulnerable groups should be protected for longer", including "older people, people with chronic diseases, and people with mental illness"[34]. By this, the EU encouraged not lifting restriction measures for these groups, without explaining how to support them.

Post-lockdown measures included measures that directly or indirectly discriminated against persons with disabilities. For instance, the obligation to wear a face mask in designated areas without providing exceptions for people who may find it difficult or distressing. Because of unclear guidance from State authorities some institutions remained closed and visits prohibited, leaving their residents in isolation, with often long-term consequences on their mental health.

Testing, vaccination, and recovery

Persons with disabilities have continued to be discriminated against in the testing and vaccination strategies and in the economic recovery plans. The communication to the European Parliament and Council on 'Preparedness for COVID-19 vaccination strategies and vaccine deployment' adopted on

October 15th did not mention persons with disabilities.On October 28th, the Commission's recommendation on COVID-19 testing also completely excluded persons with disabilities. There is also no harmonisation in European countries. While some countries already recognised that persons with disabilities should have priority access to vaccination, in others, persons with disabilities and their support networks have remained invisible.

In relation to recovery, the way EU funding is allocated changed quite drastically in light of the COVID-19 pandemic. There have been changes both to the rules for using funding in the current funding period (2014-2020), and to the way funding will be planned for the coming period (2021-2027) with a large sum of money made available solely for the purpose of recovery from the crisis in the form of the "Next Generation EU" initiative. This substantial investment is welcome and needed. It is, however, not clear how inclusive the economic and social recovery will be for persons with disabilities.

Conclusion and recommendations

While the EU and all European countries (except Liechtenstein) have ratified the CRPD, their policy and institutional approaches to disability remain ad hoc and this contributes to the marginalisation of persons with disabilities. In the case of the COVID-19 crisis, this had dreadful consequences as persons with disabilities were often only an afterthought in government actions that turned their lives upside down. In Australia, there is a Management and Operational Plan for People with Disability overseen by a dedicated Advisory Committee for the COVID-19 Response for People with Disability[35]. There does not seem to have been a similar cross-government approach in any European country.

The lack of data is a stark example of this lack of a systematic approach across governments. In most countries, governments are not gathering data on the health, social, or economic consequences of this crisis on persons with disabilities. The extent of loss of life and damage to people with disabilities' lives is unknown at the European level. Data from England and Wales reveals that during the first wave of the pandemic (March to July 2020), persons with disabilities made up 59% of all deaths involving COVID-19[36].

The level of death in institutions and other closed settings is a tragedy that even initial gaps and oversight in monitoring could not hide. Older persons and persons with disabilities have disproportionately died in these closed facilities because of the conditions in them and the lack of attention given to these populations by governments. This will be one of the most important opportunities for change that comes out of this crisis – to find new models to support community-based living.

One strength that the crisis has shown is that of the disability sector, including representative organisations of persons with disabilities and persons with disabilities themselves. Their response was immediate and robust, and often provided a leadership that led governments to make adjustments. This reiterates important doubts about government capacity on disability issues and shows the significant role organisations

of persons with disabilities play during crisis. It also shows the return-on-investment that strengthening the capacity of organisations of persons with disabilities provides and the need to ensure adequate resources for them going forward.

Persons with disabilities have been fighting for a minimum level of inclusion and recognition during the crisis. EU and national responses have been weaker and less effective, both in not targeting persons with disabilities sufficiently, and also in not taking on the lessons of disability-inclusion during this crisis. As the United Nations has made clear, “disability inclusion will result in a COVID-19 response and recovery that better serves everyone”. Involving the disability community would have shown the barriers and opportunities in the response, the people that were excluded, the adaptations needed for individuals, and the attitudes that needed to change.

A disability-inclusive response could still transform response and recovery for European countries in the future. There is an opportunity to reshape and rebuild our societies and economies in a more inclusive way for all. Throughout national responses to the pandemic there have been some improvements to responsiveness on disability but too many gaps remain. If there is a resurgence of the virus in 2021, persons with disabilities will continue to face the grave and disproportionate risks they faced this year. In addition, persons with disabilities continue to face immediate socio-economic challenges that need urgent redress.

Our 10 recommendations to the European Union and European leaders

Drawing on the dramatic consequences of the COVID-19 crisis and the immediate challenges faced by persons with disabilities, the European Disability Forum calls on the EU and European leaders to commit to:

1. **CRPD implementation**: Politically commit to ensure the rights of persons with disabilities and implement the CRPD, including in situations of risk and humanitarian emergencies such as the COVID-19 crisis.

2. **Consultation and involvement**: Adopt measures to ensure the structural and systematic involvement of all persons with disabilities through their representative organisations, and include the most disadvantaged groups, including self-advocates.

3. **Preparedness and response**: Invest in a disability-inclusive process of preparedness to prevent the devastating impacts of future crisis and ensure inclusive response. Inclusive response must include accessible public health announcements.

4. **Disaggregated data**: Ensure that all data collected is disaggregated by age, gender and disability. Persons with disabilities living in institutions or closed settings should be included in all data gathered.

5. **Adequate budget and investment:** Adequate budget must be allocated to advance the rights of persons with disabilities, their inclusion in society, the implementation of the CRPD, and the strengthening of the disability movement. Investment in recovery must include persons with disabilities. No investment must be made in initiatives that violate the rights of persons with disabilities through creation of inaccessible buildings, transport or ICT, or which segregate persons with disabilities.

6. **Accessibility and inclusion**: Ensure accessibility and inclusion of persons with disabilities at all levels of governance, response and recovery measures, and in society.

7. **Services and support**: Ensure that disability-specific and mainstream support services are available and accessible to all persons with disabilities and are recognised as essential services.

8. Independent living: End institutionalisation by immediately investing in independent living, fostering transition from institutions to community-based support services.

9. **Human rights-based approach**: Underpinning all actions with a human rights approach and the CRPD:

   - Ensuring equality and non-discrimination in legislation and practice for all persons with disabilities.
   - Protection of persons with disabilities from violence, abuse, exclusion, coercion, and neglect.
   - Ensuring continuous, independent human rights monitoring

10. Ensuring free and informed consent is guaranteed prior to vaccination.

11. **Women's rights**: ensuring the protection of women and girls with disabilities against violence and abuse, and the maintenance of accessible support services including those regarding their sexual and reproductive health and rights.

Our more detailed recommendations on COVID-19 (March 2020)

Our recommendations on vaccination (October 2020)

Endnotes

1 EU SILC 2018, except for Slovakia, Ireland and the UK for which that data is from 2017.
2 EIGE, Gender Equality Index 2019.
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4 Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor.
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8 3 S. Bagenstos (2020), "May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing", 130 Yale Law Journal Forum (Forthcoming).
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16 A. Comas-Herrera et al., "Mortality associated with COVID-19 outbreaks in care homes: early international evidence" (2020).
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18 UN Secretary-General, Policy Brief: A Disability-Inclusive Response to COVID-19 (May 2020), page 5.
19 UN DESA, Leaving no one behind: the COVID-19 crisis through the disability and gender lens.
20 Belgium, Bulgaria, Czechia, Estonia, Finland, Iceland, France, Liechtenstein, Hungary, Italy, Latvia, Lithuania, Luxembourg, Portugal, Romania, Slovakia, Spain, and Switzerland.
21 More information on the situation in each country is available in the chapter on the national response and in the annex country fiches.
22 Both the European Union, all EU member states and Iceland, Norway, Switzerland and the UK are states parties to the CRPD.
23 Denmark and Finland prohibited gathering above 10 people, Iceland above 20 people, Sweden above 50 people, and Cyprus above 75 people.

24 Lithuania authorized gathering of maximum 1000 people.
25 EDF Human Rights Report on Poverty and Social Exclusion of Persons with Disabilities (2020), pages 23-25.
26 A study indicates that in 2012, on average, 7out of 10 European citizens had Internet access at home in 2012 but only five out of ten among those who declared an activity limitation connected to impairment or disability. Scholz, Yalcin and Priestley, Internet access for disabled people: Understanding socio-relational factors in Europe (2017).
27 Data in several countries show that a majority of victims of the digital gap were persons with disabilities. For instance, data from the UK indicates that in 2017, 56% of adult internet non-users were persons with disabilities (much higher than the proportion of disabled adults in the UK population as a whole).
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29 EIGE (2020), Gender equality and long-term care at home: On average children with disabilities are more likely to live in a single-parent household, and women make up almost 85% of all single parents in the EU.
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31 The Guardian "Lockdowns around the world bring rise in domestic violence" (28 March 2020).
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33 Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor, page 10.
34 Joint European Roadmap towards lifting COVID-19 containment measures
35 See Advisory Committee for the COVID-19 Response for People with Disability, Australian Government Department of Health.
36 See Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020.

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