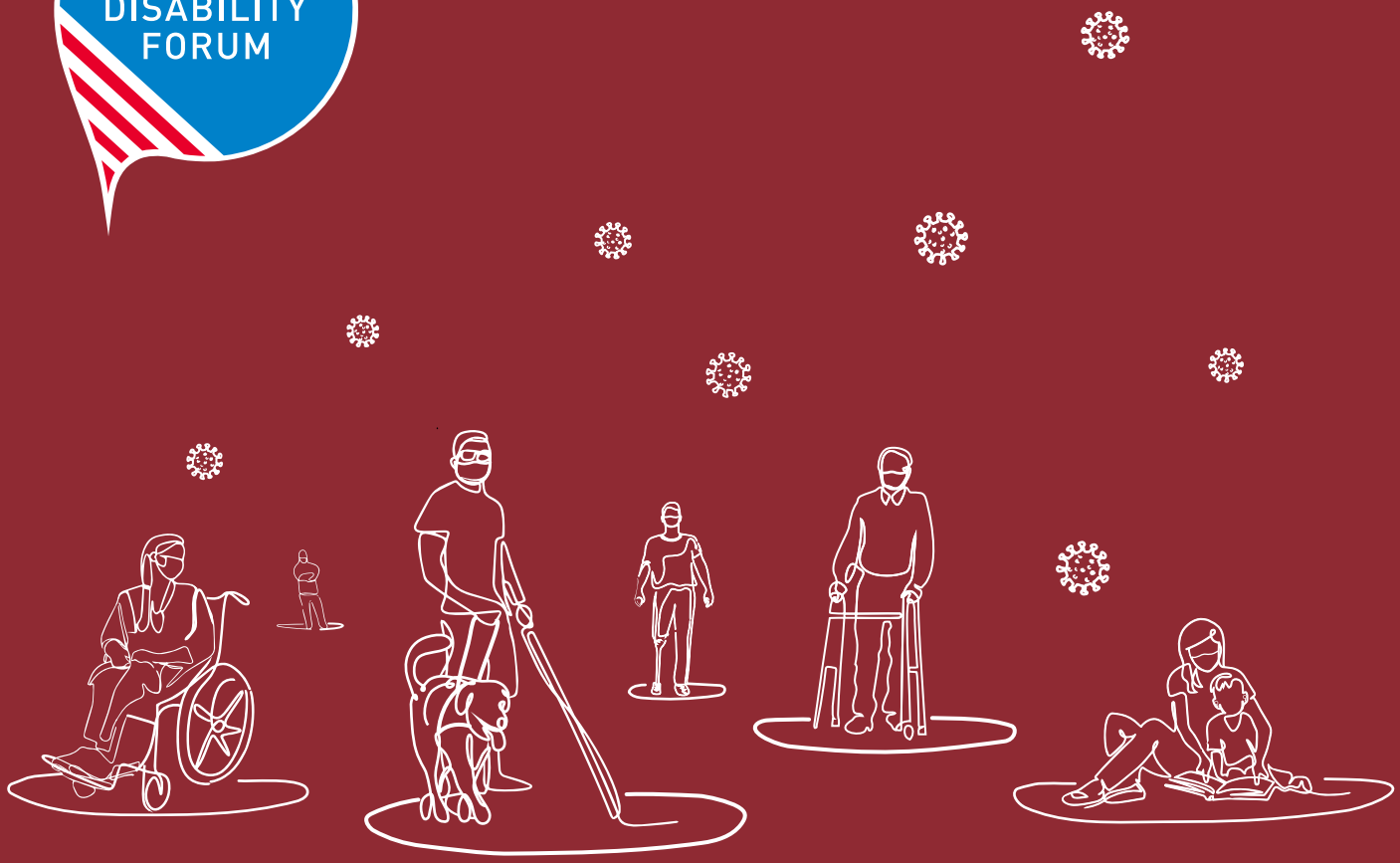
EUROPEAN DISABILITY FORUM



EUROPEAN HUMAN RIGHTS REPORT

ISSUE 5 – 2021

Impact of COVID-19 on persons with disabilities

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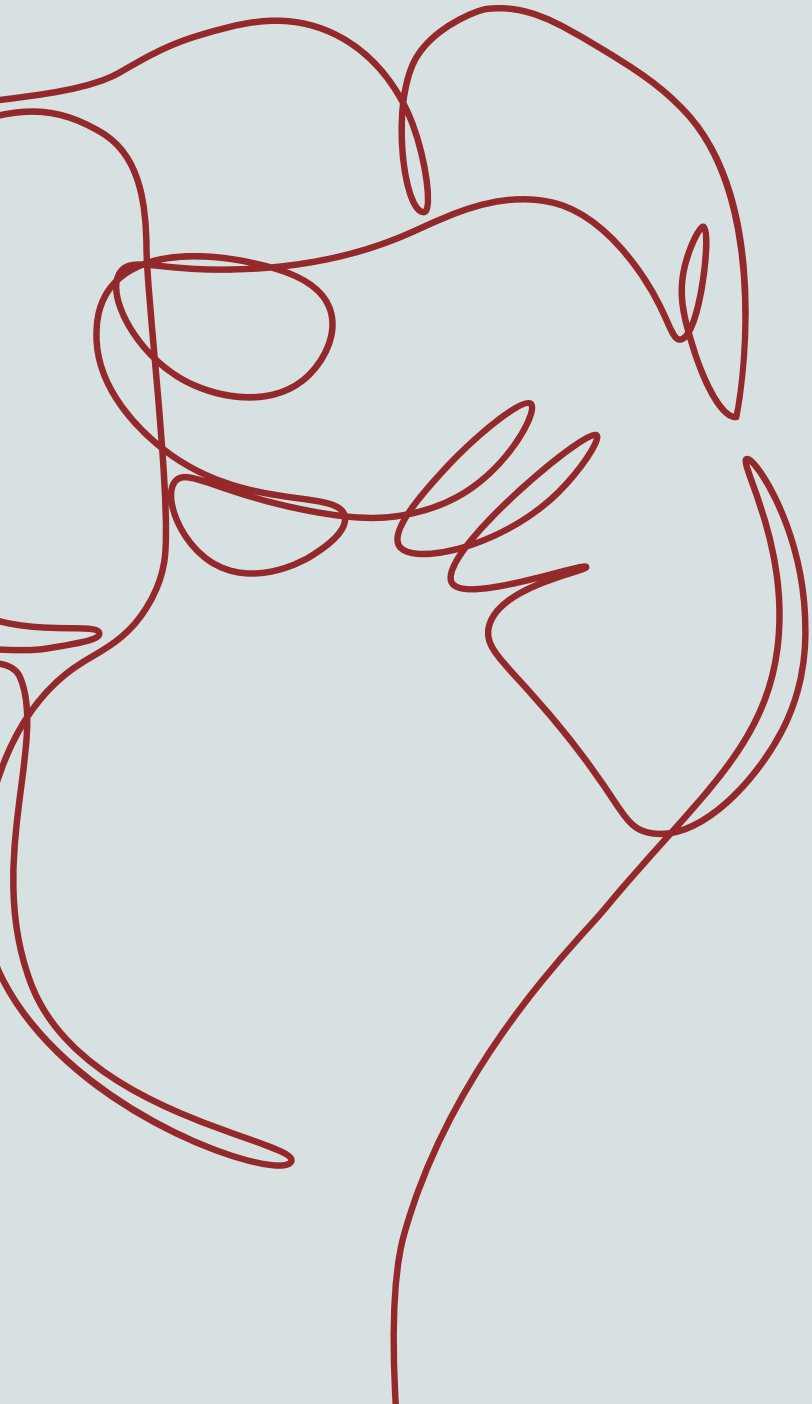


Glossary

Ageism: stereotyping and/or discrimination against individuals or groups on the basis of their age.

Braille: a form of written language for blind people, in which characters are represented by patterns of raised dots that are felt with the fingertips.

Civil society organisations: organisations within a society that work to promote specific purposes and rights, usually taken to include state-run institutions, families, charities, and community groups.

Closed settings: refers to all places where people may be living temporarily or for a long period of time that are not open to the public and not fully monitored, such as institutions, psychiatric hospitals, care centres and residences for older persons, prisons, and refugee centres.

Competences (of the European Union): areas within which the EU can act, for instance by adopting legislation. Competences are defined by the EU treaties. In other areas, the EU Member States are competent to act.

Concluding observations (of the CRPD Committee): document adopted by the CRPD Committee as part of the review mechanisms of the implementation of the Convention on the Rights of Persons with Disabilities in States Parties. The document contains areas of concerns and recommendations for improvement.

COVID-19: infectious disease caused by a new coronavirus discovered at the end of 2019. In March 2020, it was declared a pandemic meaning that it occurred worldwide affecting a large number of people.

Disability movement: global social movement working to advance the rights of all persons with disabilities and their full inclusion with society. For instance, organisations of persons with disabilities, disability activists, some human rights organisations are part of the disability movement.

Disagregated data: data that has been broken down by detailed sub-categories, for example by a disability, gender, age, or geographical

location. It can reveals inequalities that may not be apparent in non-disagregated data.

Discrimination: any distinction, exclusion, or restriction on the basis of one or several grounds (sex, race, disability, sexual orientation, gender identity, etc.) which damage or nullify the recognition, enjoyment or exercise, on an equal basis with others, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Disabled people's organisations (DPOs) / organisations of persons with disabilities: organisations comprising a majority of persons with disabilities that represent the interests and defend the human rights of persons with disabilities through self-representation and advocacy.

(EU) Directive: legislative act that sets out a goal that all EU countries must achieve. The Directive must be transposed at a national level. It means that it is up to the individual countries to decide based on their own laws how to reach these goals.

Easy-to-understand: method of presenting written or oral information to make it easier to understand. For instance, Easy to read is an easy to understand written format. It is very important for persons with intellectual disabilities.

Equality body: independent organisation in charge of promoting equality, assisting victims of discrimination, and monitoring and reporting on equality issues. Their exact mandate varies from one country to another.

Europe: continent located entirely in the Northern Hemisphere and mostly in the Eastern Hemisphere.

European Disability Forum (EDF): an independent organisation representing the rights of 100 million persons with disabilities in Europe. It is a unique platform that brings together representative organisations of persons with disabilities from across Europe and is run by persons with disabilities and their families.

Face coverings: covering of any type that covers the mouth and nose to reduce the spread of infectious agents (such as viruses or bacteria). **Face masks** are a form of face covering.

Intersectional discrimination: “Intersectional discrimination recognises that individuals do not experience discrimination as members of a homogenous group but rather, as individuals with multidimensional layers of identities, statuses and life circumstances. It means acknowledging the lived realities and experiences of heightened disadvantage of individuals caused by multiple and intersecting forms of discrimination, which requires targeted measures with respect to disaggregated data collection, consultation, policymaking, enforceability of non-discrimination and provision of effective remedies”[1].

Intersectionality: cross-over between several identities a person bears, for instance being a woman and being Roma, or being an older intersex person with disabilities.

Member States (of the EU): the EU currently consists of 27 countries, also called “Member States”. Each Member State is party to the founding treaties of the Union, and thereby subject to the privileges and obligations of membership. Unlike members of most international organisations, the Member States of the EU are subject to binding laws in exchange for their representation within the common legislative and judicial institutions.

National Human Rights Institutions: independent bodies created by States with a broad mandate to promote human rights at the national level. Their exact mandate varies from one country to another.

Poverty: defined in this publication as below the at-risk-of-poverty threshold, which is set at 60% of the national median equivalised disposable income after social transfers.

Racialised: categorisation faced by non-white people rooted in the historical and contemporary racial prejudice of society.

Reasonable accommodation: necessary and appropriate modification and adjustment, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise of their human rights and fundamental freedoms on an equal basis with others. To be “reasonable” the accommodation cannot impose a disproportionate or undue burden. Denial of reasonable accommodation is a form of discrimination.

Seclusion: being isolated and away from other people.

Self-advocates: persons with intellectual disabilities that speak up for themselves.

Service provider: person, business, or organisation who delivers funded services. Service providers have different areas of experience and expertise. In this report, it refers to all providers that deliver services to persons with disabilities.

Social distancing: better called “physical distancing,” it is a set of measures intended to prevent the spread of a contagious disease by maintaining a physical distance between people and reducing the number of times people come into close contact with each other. Examples of measures include keeping a distance of 2 meters between people and the prohibition of large gathering.

States Parties (to the CRPD): countries that have signed and ratified the CRPD and have committed to making the rights of persons with disabilities a reality. The European Union, having concluded the CRPD, is also a State party together with all its Members States.

United Nations Convention on the Rights of Persons with Disabilities (CRPD): an international human rights treaty that reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms.

EU institutions and bodies

Council of the European Union: institution representing the Member States' governments and where national ministers from each EU country meet to adopt laws and coordinate policies.

Directorate-Generals (of the European Commission): policy deparments' of the European Commission in charge of implementing and managing EU policy, law and funding programmes. List of departments.

Disability Support Groups: associations in the European Commission and the European Parliament of staff members with disabilities or with dependent with disabilities.

Disability Intergroup (of the European Parliament): informal grouping of members of the European Parliament from all nationalities and most political groups who are interested in promoting the disability policy in their work at the European Parliament and in their country.

European Foundation for the Improvement of Living and Working Conditions (Eurofound): agency of the European Union which focuses on managing research, gathering information, and communicating findings on living and working conditions.

European Centre for Disease Prevention and Control (ECDC): agency of the European Union aimed at strengthening Europe's defences against infectious diseases.

European Commission: the EU's politically independent executive arm. Its core responsibilities include proposing EU laws and policies and monitoring their implementation.

European Institute on Gender Equality (EIGE): independent body of the European Union, established to contribute to and strengthen the promotion of gender equality.

European Parliament: the elected parliamentary institution of the European Union which has the role to adopt EU legislation.

European Union (EU): a unique economic and political union between 27 European countries.

Eurostat: statistical office of the European Union.

Fundamental Rights Agency of the European Union (FRA): independent body of the European Union in charge of collecting and analysing data on fundamental rights.

Foreword

"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, including women with disabilities, and 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 governments that emergency and healthcare treatment could not discriminate us. We told govenments they needed to communicate in a way that was accessible to all. We told governments we needed to be included in the immediate response, in testing and in vaccination. We told governments that they could not segregate us anymore. We said it many times and we said it loudly.

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 advocate for 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 needs 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, their families, and support networks, who today are still disproportionately affected by the COVID-19 pandemic, victims of isolation and discrimination.

We will not stop until all persons with disabilities are included in society, in Europe and beyond. We will not stop until all institutions are closed and support to live independently and be included in the community is 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 less valuable.

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

It provides recommendations to the EU, to national governments, and to ourselves in the disability movement. We must all act now to ensure an inclusive COVID-19 recovery.

Let's build back a better and more equal world.

Yannis Vardakastanis

EDF President

Executive Summary

The fifth edition of the European Disability Forum's Human Rights Report presents the impact of the COVID-19 pandemic on person with disabilities in Europe in 2020.

It highlights how EU and European countries have largely failed to include persons with disabilities in their response to the pandemic, both within Europe and in their global response. This failure has paved the way for violations of the right to life, to health, to information, to accessibility, to equality and non-discrimination, to education, to work, to be free from violence, abuse and neglect, to liberty and security, to live independently and be included in the community, to social protection, and to be actively involved and consulted in all areas affecting our lives. The report also demonstrates the grave situation of the most marginalised and disadvantaged persons with disabilities, facing intersectional forms of discrimination. Persons with disabilities who are also women, children, older people, racialised people, LGBTI+ people, and people experiencing homelessness, prisoners, and refugees have been particularly affected.

This report shows that the situation in 2020 could be improved by the advocacy and involvement of persons with disabilities and their representative organisations.

Given the extent of the impact of COVID-19 on persons with disabilities and their support networks, we are urging EU and national decision-makers to acknowledge, consider, and implement our recommendations, presented in full at the end of the report. These include:

1. **Political commitment and investigation:** to ensure the rights of persons with disabilities at all time, including in situations of risk and humanitarian emergencies such as the COVID-19 crisis, and to investigate the impact of the governments' response on persons with disabilities. This can ensure that the same mistakes will not be repeated in future crises.
2. **Consultation and involvement:** Adopt measures to ensure systematic involvement of all persons with disabilities through their representative organisations in all decisions that affect their

lives, and include the most disadvantaged groups, including self-advocates. This requires to ensure adequate funding for representative organisations of persons with disabilities.

3. **Preparedness and response:** Invest in a disability-inclusive process of preparedness to prevent the devastating impacts of future crises and ensure inclusive crisis response. Inclusive crisis response must include accessible public health announcements and emergency communication. It must also include targetted actions to support persons with disabilities. This includes ensuring specific resources are allocated to make mainstream services inclusive and accessible, including for example vaccination programmes, employment, prevention of violence measures, emergency communications, etc.
4. **Disaggregated data:** Ensure that all data collected is disaggregated by age, gender, and disability. Persons with disabilities living in institutions and other 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.
6. **Accessibility and inclusion:** Ensure accessibility and inclusion of persons with disabilities at all levels of governance, information, response and recovery measures, service-provision, and in society. The impact of COVID-19 on European economy should not lead to deprioritsation of investment in accessibility of information and communications technologies, transport and other services, and built environment.
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:** Underpin all actions with a human rights approach and the CRPD:

- Ensure equality and non-discrimination in legislation and practice for all persons with disabilities.
- Protect persons with disabilities from violence, abuse, exclusion, coercion, and neglect, with disability, gender, and age-sensitive actions.
- Ensure continuous, independent human rights monitoring.
- Ensure free and informed consent is guaranteed prior to vaccination.

10. **Women's rights:** Ensure 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.

The report also outlines how all these actions are necessary in light of the EU and European States' commitment to the CRPD to ensure that we build back a more inclusive world following the COVID-19 pandemic and be better prepared for future crises.

Introduction

Thank you for reading our 5th European Human Rights Report.

This edition focuses on the impact of the COVID-19 pandemic on persons with disabilities. This is a very important edition to us: we have observed the devastating effect that the pandemic has had on the population of Europe and on Europe's most marginalised people. We also observed how reactions to the pandemic further excluded persons with disabilities. Our 5th Human Rights Report has the following objectives:

1. **Historical:** the report documents what happened to persons with disabilities during the COVID-19 pandemic in 2020. It gives readers, including EU and national policy makers, an overview of how COVID-19 has affected persons with disabilities.
2. **Advocacy for meaningful involvement of organisations of persons with disabilities (DPOs):** our members and partners can use this report to promote their full involvement in the plans to tackle the consequences of the pandemic. They can use it to ensure that post COVID-19 funding and policy priorities are disability-inclusive.
3. **Demonstrate the critical importance of direct consultation with persons with disabilities through their representative organisations (DPOs):** the report shows how the lack of meaningful engagement with DPOs led to serious human rights violations.
4. **Policy recommendations:** the report elaborates recommendations for legislative and policy changes. These changes would bring EU and national policies more closely in line with the CRPD, especially in case of pandemic or other emergencies.
5. **Highlight intersectional discrimination:** the report generates knowledge on the gender dimension of this crisis, and how the rights of the most marginalised persons with disabilities have been affected by COVID-19.

6. **Ensure a better recovery from this crisis and an inclusive response to future crise**s: the report provides recommendations to policymakers to guarantee that persons with disabilities are not forgotten again. It is designed to ensure full implementation of the CRPD in crisis situations based on mistakes and learnings made during the COVID-19 response. Most urgently it directs policy makers to ensure persons with disabilities have access to vaccination and to incusion in the COVID-19 recovery funding.

The report also includes positive examples of the protection of the rights of persons with disabilities by governments, human rights institutions, civil society and DPOs

Chapter 1 is common to each issue of EDFs Human Rights Report; we outline general progress on the CRPD in Europe.

Chapter 2 describes the legal and policy framework we base this report on. Chapter 3 explains how persons with disabilities have been, and continue to be, affected by the COVID-19 pandemic.

Chapter 4 goes into more detail on the impact of COVID-19 on persons experiencing extreme hardship based on additional and intersecting forms of discrimination and disadvantage.

Chapter 5 describes the EU response and outlinesways in which the EU response did, and did not, include persons with disabilities.

Chapter 6 describes the national response and how persons with disabilities have been included or excluded. There are **country response summaries** available for 32 European countries which you can refer to here, on our website.

Chapter 7 describes the response of the disability movement.

Our Conclusions and Recommendations are presented at the end of the report and are directed to policy makers both at the EU and national levels, and to ourselves in the disability movement.

Methodology

In order to complete this report, we have used a range of methods. From the beginning of the COVID-19 pandemic the European Disability Forum communicated daily with its members on how COVID 19 was impacting them. EDF followed the EU response and advocated for improvements at each stage. Our members have been monitoring and participating in the response at the national level. Meetings and public online events were organised with our members and partners to monitor the COVID-19 response in Europe. Recordings of webinars, statements and an overview of the actions and response of our members is available on our website.

We are using several sources of data:

- Data gathered internally on the EU response – through collection of public sources and private contacts
- Data gathered by our European and National members
- Data gathered by equality bodies, national human rights institutions and other partners to monitor human rights of persons with disabilities

Due to the constant evolution of the COVID-19 crisis, some data presented in the report will be outdated by the time it is published. We recommend readers consult the references for more information on the source and date of the data presented. All data have limitations and rely on the methodology used by the body that conducted the collection. In many cases, data is missing because it was not collected by governments. Data available in each country varied and very few countries had data disaggregated by disability. The sources we refer to are available in the footnotes.

We have worked directly with our members in the analysis of data and in creating recommendations from the original concept note to the drafting and completion of this report. In particular, our Board and Executive committee, our youth committee, and women's committee have given their inputs to review and enrich this report.

Chapter 1: CRPD update in Europe

The Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty reaffirming that persons with disabilities enjoy all human rights and fundamental freedoms. It clarifies that persons with disabilities have the right to participate in civil, political, economic, social and cultural life in the community, just like anyone else. It stipulates what public and private authorities must do to ensure and promote the full enjoyment of these rights by all persons with disabilities.

It was adopted in 2006 by the General Assembly of the United Nations (UN). 181 countries including the European Union (EU) are States Parties to the CRPD. It is also the world's fastest-ratified international human rights treaty[2].

Ratification of the CRPD

In Europe, the CRPD has also been ratified rapidly. The EU has been a State Party to the CRPD since 2011. All EU member states have ratified the CRPD. Other countries in Europe have also ratified: Albania, Andorra, Iceland, Monaco, Montenegro, North Macedonia, Norway, San Marino, Serbia, and Turkey. Liechtenstein is the last country that has not ratified the CRPD in Europe[3].

EDF calls on Liechtenstein to ratify the CRPD without further delay.

Map of the ratification of the CRPD in Europe

1. Belgium
2. Netherlands
3. Luxembourg
4. Switzerland
5. Monaco
6. Andorra
7. San Marino
8. Austria
9. Slovakia
10. Slovenia
11. Croatia
12. Bosnia and Herzegovina
13. Serbia
14. Montenegro
15. Albania
16. FYROM

Submission of initial report to the CRPD Committee

States Parties are obliged to submit an initial report to the CRPD Committee on measures taken to implement the CRPD, two years after the CRPD comes into force in their country. Some EU Member States have not sent in their first state report to the CRPD Committee, thereby blocking the Committee's review process. This is the case for the following countries: Iceland (state report was due 23rd October 2018), Ireland (state report was due 20th March 2020), Romania (state report was due 2nd February 2013) and San Marino (state report was due 22nd March 2010).

EDF calls on Iceland, Ireland, Romania and San Marino to urgently submit their initial state report to the CRPD Committee.

Submission of initial State report to the CRPD Committee

Countries that have not submitted their initial state report

Optional Protocol to the CRPD

The Optional Protocol to the CRPD allows individuals, groups of individuals, or third parties to submit a complaint to the CRPD committee about human rights violations. Complaints may only be made against a State Party that has ratified the Optional Protocol. If the CRPD Committee makes a finding that the State Party has failed in its obligations under the CRPD, it will issue a decision requiring that the violation be remedied and for the State Party to provide follow-up information.

Twenty-two EU Member States, as well as all EU candidate countries and the United Kingdom have ratified the Optional Protocol. Norway, Iceland and Liechtenstein have not ratified it.

The CRPD Committee calls on each State Party to ratify the Optional Protocol.

EDF calls on the EU, as well as Bulgaria, Czechia, Ireland, the Netherlands, Poland, Romania, Iceland, Liechtenstein, Norway and Switzerland, to ratify the Optional Protocol.

You can read the full text of the CRPD and the Optional Protocol on the web page of the CRPD Committee[4].

Ratification of the Optional Protocol of the CRPD

- Countries that have not ratified the Optional Protocol
- 1 the Netherlands
- 2 Czechia
- 3 Switzerland
- 4 Liechtenstein
- European Union

Chapter 2: Legal and policy framework

Various international and EU legal and policy frameworks are relevant to protect the rights of persons with disabilities in time of crisis such as COVID-19. The frameworks described below are unconditional and should always be respected, including in time of pandemic. Their implementation was explained in various guidance and policy documents, mostly adopted at the level of the United Nations.

International level

UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (CRPD) has given the disability movement a strong legal framework to advocate for the rights of persons with disabilities, including in times of crisis such as the COVID-19 pandemic. The human rights violations experienced by persons with disabilities in Europe during the COVID-19 pandemic cut across the whole of the CRPD.

The UN Committee on the Rights of Persons with Disabilities (CRPD Committee) and other bodies of the United Nations started reacting to the pandemic from a disability perspective in April 2020, once most European countries were already in lockdown. Here is a list of some of the resources produced by the UN in 2020:

- OHCHR guidance note: COVID-19 and the rights of persons with disabilities: Guidance (29 April 2020)
- UN Secretary-General's Policy Brief: A Disability-Inclusive Response to COVID-19 (May 2020)
- UNDESA policy brief focusing on the impact of covid-19 on women and girls with disabilities: Leaving no one behind: the COVID-19 crisis through the disability and gender lens (June 2020)
- UNICEF webpage on Child disability and COVID-19 including several guidance notes
- Joint statement, Persons with Disabilities and COVID-19 by the Chair on behalf of the CRPD Committee and the Special

Envoy of the United Nations Secretary-General on Disability and Accessibility (1 April 2020)

- Statement on COVID-19 and the human rights of persons with disabilities by the CRPD Committee (9 June 2020)

More UN resources

2030 Agenda for Sustainable Development

The 2030 Agenda for Sustainable Development, including its 17 Sustainable Development Goals (SDGs) are an international commitment to eradicate poverty and achieve sustainable development world-wide by 2030, recognising the importance of empowering people in vulnerable situations, including persons with disabilities. The SDGs are vital for a recovery that leads to greener, more inclusive economies, and stronger, more resilient societies.

Sendai Framework for Disaster Risk Reduction

The Sendai Framework for Disaster Risk Reduction 2015-2030 is part of the post-2015 development agenda that provides countries of the United Nations with concrete actions needed to protect populations from the risk of disaster. It aims to build the resilience of society to disaster risk by reducing their vulnerabilities and addressing the hazards that they are exposed to. The Sendai framework recognises the need for disability disaggregated data, that persons with disabilities should be empowered to lead, promote, and assess disaster risk reduction and humanitarian activities, and that universal design and accessibility are essential to achieve effective 'Build Back Better'. The EU and many of its Member States participated in the development and adoption of this framework. Throughout 2016 the EU also participated in deciding the steps required for Sendai to be effective, and has developed a specific EU Action Plan on Sendai implementation.

Charter on Inclusion of Persons with Disabilities in Humanitarian Action

The Charter on Inclusion of Persons with Disabilities in Humanitarian Action can be seen as a 'tool' to implement the CRPD in situations of risk and humanitarian emergency. It was launched at the 2016 World

Humanitarian Summit. Since then, it has been endorsed by the EU and 14 of its Member States[5].

In June 2019, the European Commission published a Guidance Note on the Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations. This guidance note is related in purpose to the UN IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action which were launched at the end of 2019.

European Union level

The EU's ratification of the CRPD commits it to ensure the rights of persons with disabilities in all its laws, policies and activities.

Several legal and policy instruments and frameworks are relevant to ensure disability inclusive responses to COVID-19. This section is not exhaustive and covers the main framework and instruments identified by EDF: the EU Fundamental Rights Charter, the EU Disability Rights Strategies, the use of the EU funds in line with the CRPD, the European Pillar of Social Rights, and the EU Semester.

European Charter of Fundamental Rights

The Charter of Fundamental Rights of the European Union (the Charter) brings together the fundamental rights of everyone living in the EU. The Charter is legally binding in the EU. It means that all the institutions and bodies of the EU need to respect the rights contained in the Charter when drafting EU law and policy. At the national level, policymakers should respect the Charter when implementing EU law. It continues to apply in times of emergency. The rights of persons with disabilities are included in Articles 21 and 26 of the Charter. The Charter goes on to state in Article 35 that a high level of human health protection shall be ensured in the definition and implementation of all EU policies and activities.

European Disability Strategies

The European Commission is in the final stages of its European Disability Strategy 2010-2020, and in early 2021 will adopt its next Disability Rights Strategy. The 2010-2020 strategy paved the way for advances on disability policies during the decade. It focused on eliminating barriers in eight main areas: accessibility, participation,

equality, employment, education and training, social protection, health, and external action. It was not, as has been highlighted by the CRPD committee to the EU in 2015, a comprehensive strategy for the implementation of the CRPD.

European Pillar of Social Rights

Proclaimed in 2017 by the EU institutions, the European Pillar of Social Rights sets out 20 key principles and rights to support fair and well-functioning labour markets. It includes a specific principle - principle 17 - dedicated to persons with disabilities. All principles are also relevant to persons with disabilities, for instance equal opportunities, minimum income, access to health.

European Semester

The European Semester provides a framework for the coordination of economic policies across the EU. It gives information about the situation of persons with and without disabilities in the Member States. It consists of multi-annual discussions between the European Commission and Member States to achieve the EU's targets.

In recent years, the Country Specific Recommendations have made increasing reference to persons with disabilities. The Recommendations for 2020 also took into account the particular impact of the COVID-19 pandemic on persons with disabilities.

The most common disability-specific issues covered, in order of frequency, were the following:

- Employment of persons with disabilities
- Poverty and social inclusion of persons with disabilities
- Social services and community-care
- Social protection for persons with disabilities
- Accessible health services
- Accessible distance learning for learners with disabilities during COVID-19
- Lifelong learning

Chapter 3: Persons with disabilities and the COVID-19 crisis

This chapter gives an overview of the impact of COVID-19 on persons with disabilities in Europe. It not only shows how persons with disabilities have been at an increased risk of being infected by the virus, developing serious illness and dying, but also how they faced discrimination and human rights violations at each stage of the crisis. Chapter 4 explores intersectional forms of discrimination and disadvantage in more detail.

Over 100 million persons with disabilities live in the European Union, with a much higher number if we consider the European continent. Before COVID-19 hit Europe, a large percentage of persons with disabilities were living in precarious situations and at the margins of society. More than 28% of all persons with disabilities were currently living in poverty and experiencing social exclusion in 2018[6]. Only 20.7% of women with disabilities and 28.6% of men with disabilities were in full time employment in 2019[7]. Some issues faced by persons with disabilities (including discrimination, poverty, and social exclusion) have been addressed in previous Human Rights Reports of EDF[8].

Adding to these issues, several other social factors have increased the risks of persons with disabilities from COVID-19.

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

Because of a variety of factors described below, persons with disabilities have been more likely to be infected by COVID-19, develop serious illness or die, or find themselves isolated, impoverished, and facing increased hardship in the future.

Medical conditions and unmet needs for healthcare

Pre-existing medical conditions have been considered high-risk factors for COVID-19 infection. While some health conditions associated with disability result in poor health, 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[9]. Overall, persons with disabilities are more susceptible to secondary conditions and co-morbidities, such as lung problems, diabetes, heart disease, and obesity, which can worsen the outcome of COVID-19 infections[10].

Barriers in access to healthcare

Because of inaccessibility and discrimination, persons with disabilities have greater difficulties in accessing healthcare and life-saving interventions, including in times of pandemic. In some countries, persons with disabilities are directly discriminated against through triage protocols or indirectly discriminated against due to de-prioritisation[11]. This is often due to discriminatory criteria, such as older age, or assumptions about quality or value of life based on disability[12]. Even in situations where discrimination may not be present, persons with disabilities may wait longer or not seek treatment because of fear of not being treated[13].

Older age

The World Health Organisation considers older age a risk factor for COVID-19[14]. This is also linked to disability, as there is a higher percentage of older persons with disabilities – whether they have always lived with disability or acquired it at a later stage in life. Worldwide, an estimated 46% of older people aged 60 years and over are persons with disabilities[15].

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 with disabilities, represent most people in institutions globally[16]. Although there is no official data on the number of people living in institutions in the EU, we estimate at least 1 million persons with disabilities are living in such settings[17].

People living in institutions, residential settings, and care homes had limited access to COVID-19-related information, testing, and healthcare. They also faced difficulties in implementing hygiene and protection measures[18]. In Romania, the disability movement strongly condemned the discriminatory actions taken in relation to the outbreak

of COVID-19 in a psychiatric institution where 242 of the 369 residents and 59 of the 86 members of staff had been infected[19].

Data available indicates that people in institutional settings are facing the highest rates of infection and mortality from COVID-19[20]. In Slovenia, for instance, 81% of the COVID-19 deaths were among care home residents[21].

Barriers in implementing hygiene and protection measures

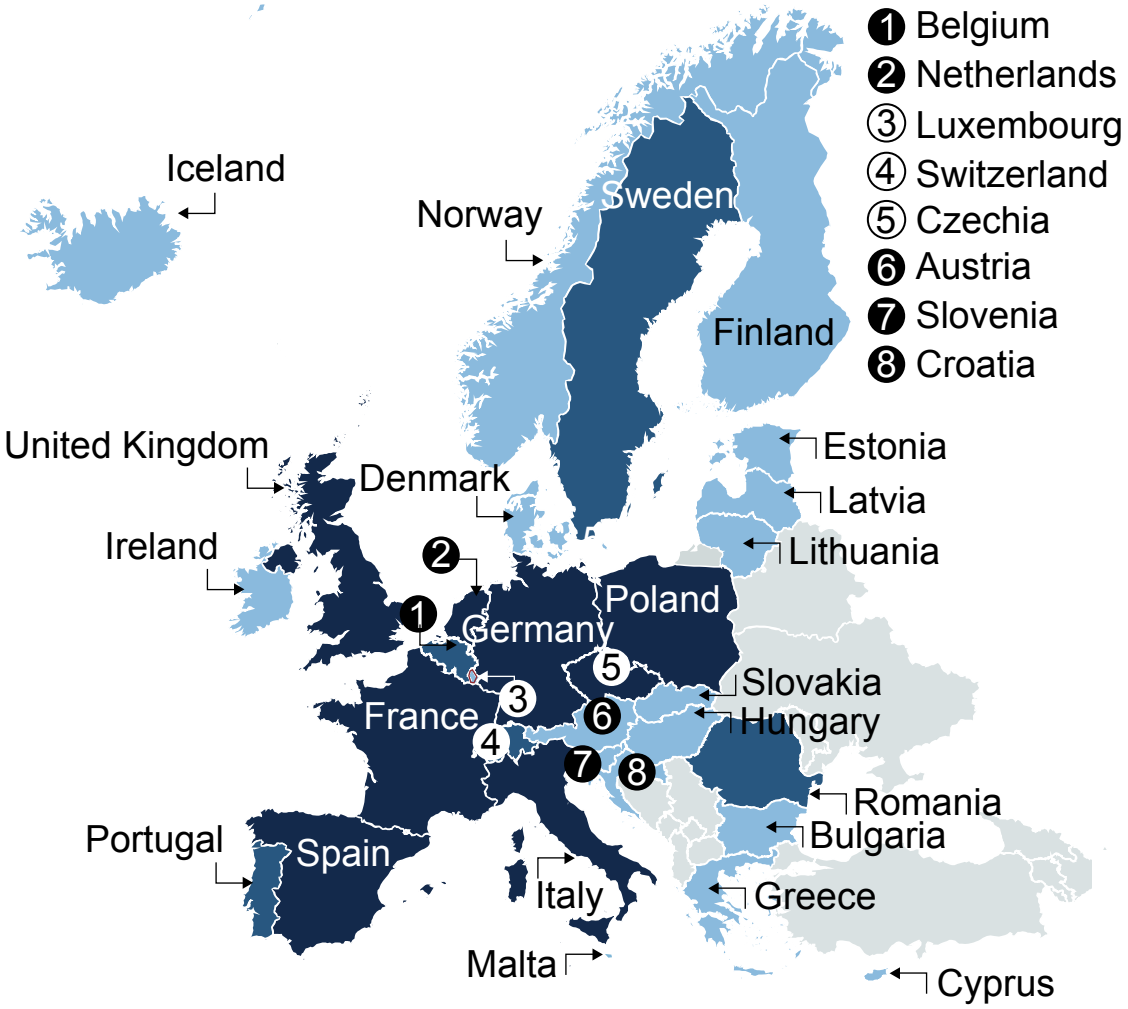
Persons with disabilities often face barriers in implementing the hygiene and protection measures put in place by governments. For instance, they may have difficulties in washing their hands often or respecting social distancing due to a variety of factors: lack of accessibility of water, sanitation and hygiene facilities, a reliance on physical contact to get support, inaccessibility of public health information, or being placed in institutional settings that are often overcrowded and unsanitary[22]. Some persons with disabilities may also find it difficult to wear face masks.

Multiple and intersecting disadvantage and discrimination

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 health care comparing to men without disabilities[23]. The United Nations denounced the 'appalling impact' of COVID-19 on racial and ethnic minorities due to a range of factors also including discrimination, unequal access to healthcare, and poverty[24].

Impact of the pandemic- number of infections and deaths (between January 2020 and December 31st 2020)

Impact of the pandemic. Number of infections (between January 2020 and December 2020)



Impact of the pandemic. Number of deaths (between January 2020 and December 2020)

Overview of the phases of the pandemic and government response

On 31st December 2019, the Wuhan Municipal Health Commission, in China, reported a cluster of cases of pneumonia in Wuhan, 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 and Iceland, Liechtenstein, Norway, Switzerland, and the UK), 17 countries declared a state of emergency[25] and most 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 Bulgaria, Croatia, Denmark, Germany, Hungary, Iceland, Liechtenstein, Luxembourg, Malta, Slovakia and Sweden[26].

The European Union, through the Council of the EU representing Member States, and the European Commission took specific steps to address the pandemic. These are addressed in Chapter 5 on the EU response to the pandemic.

An analysis of the response to the pandemic illustrates the lack of consideration of disability rights and states' obligations under the CRPD: from preparedness to recovery, persons with disabilities were left behind. This led to widespread human rights violations and the deaths of persons with disabilities across Europe. Societies that were not inclusive to begin with could not ensure an inclusive response to the pandemic.

Preparedness (before COVID-19)

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, the EU and European countries were not fully prepared for a pandemic and not prepared for a disability-inclusive response. Persons with disabilities had not been

consulted on preparedness, disability support services were not on the list of essential services, and there was no specific attention given to older people and people in closed settings such as institutions.

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, in particular representative organisations of persons with disabilities.

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 (DPOs) in all matters that concern them (Article 4.3) and ensure equality (Article 5) and access to health (Article 25).

This is something the EU and European countries failed to do from the beginning of the pandemic. The first response was slow and reflected negative stereotypes about persons with disabilities. Assuming that the virus was mostly dangerous for "the most vulnerable", including people with compromised immune systems, older people, and persons with disabilities, many countries started taking measures once a higher number of cases and deaths affecting people outside these groups were reached. Some countries were even promoting, either officially or unofficially what is known as a 'herd immunity approach' allowing the disease to spread- as it only killed certain people, deemed less valuable[27].

Communication 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 sign languages or international sign interpretation. This also affected people with intellectual disabilities and autistic people because of the lack of information in plain language and Easy to Understand formats.

In most countries, organisations of persons with disabilities were not proactively consulted by their governments. The role of the disability movement is addressed in **Chapter 7**.

Lockdown and/or restrictions measures

Lockdown, state of emergency, and temporary restrictions meant that the lives of all Europeans 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 restricted gatherings were permitted to a maximum of between 10[28] to 1000 people[29]. Almost all countries adopted travel bans, closed their borders, or installed border controls of some sort. Over the summer months of 2020, restrictions and lockdowns were lifted, or partially lifted, in several countries.

Governments have mostly failed to consider the rights and inclusion of persons with disabilities in their lockdown measures. They have also failed to prevent human rights violations from occurring. Key issues faced by persons with disabilities at a national level are described in **Chapter 6** on national responses and in the country response summaries available on EDF's website. They include issues regarding access to education, employment and healthcare services, gender based and domestic violence, human rights violations in institutions, and disability support services.

Lifting of lockdown and restrictions

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

For example, 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"[30]. By this, the EU encouraged countries to not lift restriction measures for these people, 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 States' authorities, some institutions remained closed and prohibited visits, leaving their residents in isolation often with long-term consequences on their mental health.

In October 2020, new restrictions and partial lockdowns were announced in several countries following a "second wave" of COVID-19 cases. In November 2020, the number of countries imposing strict lockdowns increased.

In December, as the year ended, many countries are in very strict lockdown including Belgium, Czechia, Ireland, the Netherlands, France, Germany, and the United Kingdom.

Access to testing, treatment and vaccination

Access to COVID-19 testing and treatment has been limited across the EU, at different points during the crisis[31]. Development of testing capacity has been slow, but it has enabled governments to more clearly identify people infected and to create more targeted COVID-19 responses. Persons with disabilities lacked priority access to testing and faced exclusion and discrimination in lifesaving treatments.

In October, in anticipation of vaccines being approved, the European Commission launched its vaccinaiton strategy. It called on governments to make the COVID-19 vaccine a public good, free for every person. EDF strongly objected to the exclusion of persons with disabilities in this vaccination strategy[32], and by December had received clarifications from the Commisioners for Health and for Equality that persons with disabilities were included considering the range of risks they face during the pandemic[33].

In November, there was positive news on vaccination, with a number of newly developed vaccines showing high levels of efficacy.

In December 2020, the UK approved a vaccine and began its vaccination programme, focusing on health workers and older people. The European Medicines Agency recommended the first COVID-19 vaccine for authorisation in the EU on December 21st 2020[34], paving the way for vaccination roll-out to begin before the end of 2020.

The European Centre for Disease Prevention and Control has collected an overview of different countries' vaccination strategies and vaccination deployment plans. So far, only Spain refers to persons with disabilities for priority vaccination, but only those in institutional settings[35]. In a report of October 26th, the European Centre recognised that persons with disabilities could be a potentially targeted group[36].

The EU and European countries have started to take measures on economic recovery. They are described in the chapter on the response of the European Union.

Chapter 4: Multiple and intersectional forms of discrimination and disadvantage

Persons with disabilities are not a homogenous group. They are individuals with multidimensional layers of identities and life circumstances. This chapter goes beyond the impact of COVID-19 on persons with disabilities in general to look at how persons with disabilities have experienced multiple and intersectional forms of discrimination and disadvantage. Despite the reality that people bear multiple identities, little information on intersectionality and COVID-19 was available at the time the report was written. This chapter offers a non-exhaustive overview of issues faced by persons with disabilities with multiple identities and/or in disadvantaged situations. These identities are listed in alphabetical order.

Children and young persons with disabilities

There is no data on the number of children and young persons with disabilities living in the European Union, or in Europe. Despite this lack of information on their number and situation, research indicates that multiple discrimination faced by children and young persons with disabilities includes limited access to quality, inclusive education, institutionalisation, and violence.

Limited access to education

During COVID-19 one of the key issues for children and their families was access to education. As most schools closed during the strictest lockdowns, distance learning often excluded children with disabilities. Many governments failed to immediately address challenges in ensuring special education needs and support for learners with disabilities. Students did not have access to their support persons, and for many distance learning was not accessible, leading to students with disabilities being left behind[37].

While some schools made progress in adopting inclusive measures, for instance by investing in new digital tools and providing support, issues still emerged for children with disabilities returning to school in September.

Many children with disabilities and complex support needs have been excluded from schools. In England, almost a fifth of students with special educational needs have been missing out on school[38]. Such issues have also affected students with disabilities attending higher education. For instance, the University of Stockholm, Sweden, only proposed online classes and closed its "resource rooms" that provided support to students with disabilities[39]. More information on access to education is available in Chapter 6 on the national response[40].

Impact on the daily life and mental health of young persons with disabilities

After the first wave of COVID-19 in Europe, EDF conducted a survey to learn more about the experience of young people with disabilities during the crisis[41]. Respondents were asked about how the pandemic impacted their lives in terms of access to support, social life, education, employment, and physical and mental wellbeing. Responses were received from Belgium, Iceland, Italy, Germany, Greece, Malta, Spain, and the UK. 62% of respondents were identified as women and 38% as men.

68% of respondents said that the pandemic had an impact on their mental health. When asked to explain, respondents spoke about stress, isolation, anxiety and depression. The survey asked respondents to rank out of 10 their level of mental health before, during and after the lockdown, and the results are displayed in the graph below. A majority (66%) of respondents charted their mental health decreasing or dipping during the lockdown period.

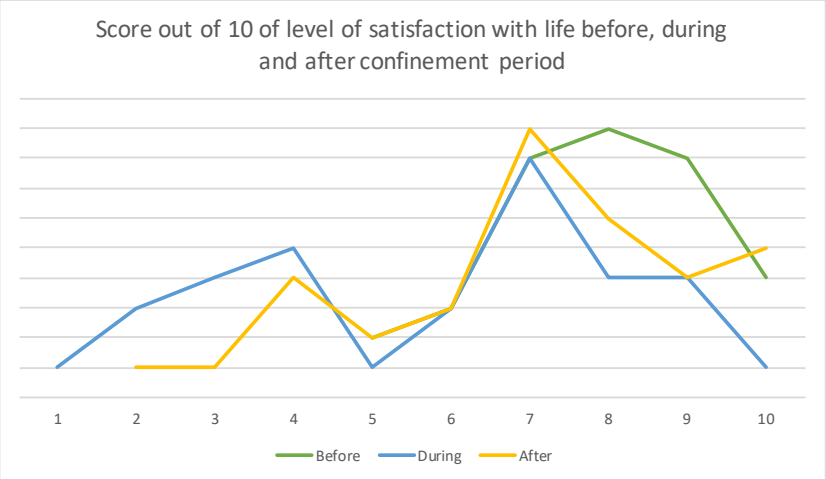


Figure: Graph tracking levels of satisfaction with life of survey respondents

When asked how their life had changed since the period of lockdown, some responses were related to the practical changes to routine, others about restricted contact with friends and family, changes in financial situations and stability, and about changes in perspective and priorities. With regard to the question of whether they felt any fear about the future, respondents described concerns about attending school, seeing friends, lack of leisure activities, and general isolation.

Testimony: Francesca Sbianchi, young woman with disabilities from Italy – member of EDF Youth Committee

"Everything changed with COVID-19, which marked a divide between 'before' and 'after' it. The way of living, relating and interacting with others has totally changed due to the need to avoid the spread of the virus. Social distancing made us live affectivity in a different way, mainly with verbal interaction. That is why relationships represent one of the most complex aspects to be managed. In such a situation, close, truthful relationships last and may even be strengthened, while more superficial ones may come to an end.

From a personal point of view, I have a positive approach, so I can say that, on the one hand, the use of technologies was useful to cope with the difficulties arising from the situation. Smart working solutions allowed for reasonable accommodation. I think, however, that in the future when the situation is back to 'normal' we must ensure that persons with disabilities have freedom of choice on how to carry out their work.

On the other hand, technologies can also be a barrier. Regarding education, in fact, blind children who have no computer skills are not able to access learning platforms by themselves and, not having any professional support at home during the lockdown, families had to make up for it, when possible.

Even on a personal level, persons with disabilities have been put to the test because those who were perseveringly committed to empowerment and rehabilitation activities have been forced to suspend/interrupt them in favour of personal and collective security. In this sense, social inclusion has been neglected or overshadowed."

Girls and women with disabilities

There are over 60 million women and girls with disabilities living in the European Union (60% of the population of persons with disabilities).

Before the pandemic, women and girls with disabilities were already at higher risk of facing discrimination, abuse, and violence, compared to men with disabilities or women without disabilities. For instance, women with disabilities are two to five times more likely to be victims of violence than other women, and on average 34% of women with disabilities have experienced physical or sexual violence by a partner in their lifetime[42]. Women and girls with intellectual disabilities are particularly exposed to violence, including specific types of violence in residential institutions[43]. Women with disabilities also face higher rates of unemployment, with only 20.7% being in full time employment (compared to 28.6% of men with disabilities, and 48% of women without disabilities)[44], and a higher poverty rate.

Domestic and sexual violence

Data shows that since the start of the COVID-19 pandemic, and especially during lockdown measures, violence against women and domestic violence has intensified. For example, in France, reports of domestic violence have increased by 32% during the lockdown[45] and in Cyprus, helplines have received an increase in calls of 30%[46]. In France, the helpline specific for women with disabilitiescreated and managed by the organisation of women with disabilities Femmes pour le Dire, Femmes pour Agir, received less calls during the first lockdown (maybe due to the presence indoors of the aggressor), but an increase in calls after the lockdown and a strong increase in quantity and strength of violence during the second lockdown and after[47].

Although we do not know the proportion of women and girls with disabilities who were 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 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. While the European Institute of Gender Equality (EIGE) reported that all main helplines remained open during the lockdown, it did not state if they were accessible and inclusive for victims with disabilities. For instance, some helplines may not be accessible to Deaf, Deaf-blind and hard of hearing women. Furthermore, the list of helplines published on the EIGE's website[48] is not accessible to women using a screen-reader.

Violence and abuse in institutions

During the lockdown, many women and girls with disabilities living in institutions were trapped inside, without the possibility to leave or see their families. In some cases, they were not even able to communicate with their family or people close to them. A report published by Inclusion Europe in 2019, illustrates the multiple forms of violence faced by women and girls in institutions, from verbal violence and harassment, to beating and rape[49].

Testimony: Magdalena Kocejko, Feminist with disabilities from Poland (Article 6 Collectif)

"There is no data or any other research about the situation of women with disability in care homes during pandemic, but the overall reality has been dramatic. According to Polish Disability Forum the risk of death from COVID-19 is several dozen times higher than outside institutions. In many care homes people have been staying locked up since March without any possibility to go outside or meet their family. There has not been any policy solution to address the problems of human rights violations, isolation and increasing risk of psychological, sexual and physical abuse. It is safe to assume, that women with disabilities have been particularly disadvantaged. These institutions have remained closed to the public so there is no way to get help in case of abuse or psychological crisis."

Violence taking place in institutions and other closed settings has been very hard to monitor since the beginning of the pandemic. Some national human rights institutions have conducted monitoring visits, but they were limited due to lack of personal protective equipment.

Italy "Stuck in institution, raped by her carer"[50] by Luisa Bosisio Fazzi, EDF Women's Committee

In Mach 2020, the military was deployed to "protect" persons living in Troina Oasis, an institution for persons with intellectual disabilities in Italy, during the COVID-19 lockdown. Their presence did not prevent or detect the abuse and rape faced by a woman with disabilities. While they managed the COVID-19 outbreak that led to 160 infections in the institution, nothing prevented the rape of one (or more) of their residents. The rape in question was discovered by the family of the victim, once the institution was re-opened for visits. She was pregnant. The staff of the institution seemingly did not know.

Only after reporting it to the management did they investigate and, with confirmation of the pregnancy, made a report to the judiciary. The police then acted quickly and identified in a few days the rapist. He was arrested after confessing to the rape.

Limited support for victims and barriers in access to justice

Legal services and support for victims were already limited for women with disabilities, with helplines and information not always accessible to women with disabilities. This has become worse during COVID-19. The UN Office for Human Rights reported that alongside other risk factors, it is likely that many women with disabilities are unable to report or call helplines, as many are not equipped with interpretation services for Deaf and Deafblind persons[51]. For example, in the United Kingdom, Deaf women reported having difficulties communicating since all communication is now occurring via phones[52]. Regarding shelters, even when shelters were open, women with disabilities were unable to access them because the emergency shelters cannot accommodate them due to inaccessibility[53].

Testimony: Magdalena Kocejko, Feminist with disabilities from Poland (Article 6 Collectif)

"The COVID-19 response in my country was disability and gender insensitive. Women with disabilities stayed invisible and their situation was unrecognised.

Lockdown has increased the level of domestic violence, but on the governmental side there was no attempt to address this problem at any level. Insufficient finances, staff shortages and lack of recognition of special needs and accessibility has prevented women with disabilities from getting necessary support when needed. There has been no helpline for Deaf women available nor access to information in easy-to-read format. As a result, it has been problematic for many women with disabilities to even have access to information about their rights and get the support they needed. Women with disabilities have been left alone without any support."

In addition, access to justice has slowed down since the beginning of the pandemic. With restriction measures in place, on-going proceedings may have been paused, and new complaints were processed slowly. Sisters of Frida, a collective of women with disabilities in the United Kingdom, reported that due to the quarantine orders, women with disabilities have had less access to their one-on-one advocates[54].

Limited access to sexual and reproductive health and rights

Pre-crisis, women and girls with disabilities already had more difficulties in exercising their sexual and reproductive health rights. Because of myths, stereotypes, and lack of knowledge of disability, they face discriminatory treatment and abuse (including forced sterilisation, contraception, and abortion), with important and sometimes irreparable consequences on their lives[55].

During the pandemic, some States have attempted to limit access to some sexual and reproductive health services, particularly abortion, by classifying them as non-essential services or attempting to adopt laws that further restrict access to them. This was, for instance, the case in Poland. The Constitutional Tribunal in Poland has ruled that

the law permitting abortion on grounds of "a severe and irreversible foetal defect or incurable illness that threatens the foetus's life" was unconstitutional. It has triggered mass protests across Poland and many women with disabilities decided to join the protests[56]. In Italy, some hospitals stopped providing abortion services and sent women needing sexual and reproductive healthcare to other hospitals, making obtaining an abortion much more complicated[57].

Homelessness and Persons with disabilities

Persons with disabilities are at a higher risk of extreme poverty leading to homelessness than the general population[58]. Although there is no EU data on the number of homeless people with disabilities, where data does exist, it reveals that they are largely overrepresented when it comes to homelessness. For example, a study carried out in the Netherlands in 2014 that observed 387 participants, found that 29.5% of homeless people had an intellectual disability, whereas the prevalence of intellectual disabilities among the population as a whole is around 0.7%[59]. In 2016, in Ireland, the rate of disability among homeless people was 27%, double that of the general population (13.5%)[60].

A report from the European Anti-Poverty Network (EAPN) highlights that people experiencing homelessness are a medically high-risk population, disproportionally affected by poor health and disability, and facing higher risks of dying if they contract COVID-19. Like the general population of persons with disabilities, they face multiple barriers to accessing healthcare as well as public health information[61]. In addition, transmission within the population of people experiencing homelessness was difficult to contain as they did not have the option to stay at home[62].

Testimony: homelessness and isolation in London[63]

"I am homeless and need supported accommodation believe nothing else is suitable due to my needs (abuse/trauma after fleeing domestic violence and fearing being abused). I'm also autistic so not getting support to actually learn how to rent a house and rebuild my life. Mental health is suffering too. Can't work. This has been ongoing for nine months now since I first tried escaping. But COVID has messed it up as I was close to hopefully getting what I need."

In many countries, in addition to disability services, day services for homeless people providing food and medical services ceased during the pandemic. While it is also reported that some countries kept their shelters functioning or opened alternative facilities to host people experiencing homelessness[64], it is not clear whether they were accessible to homeless persons with disabilities. In many cases, places were overcrowded, increasing risks of getting the virus.

Homeless people faced additional abuse during the pandemic, particularly impacting homeless people with mental health issues. For example, in some countries (Belgium, Spain, United Kingdom) homeless people were chased out of public spaces and harassed by the police, without being assisted to find a shelter[65]. In the Netherlands, a homeless woman who got infected by COVID-19, instead of being given a place to quarantine and get medical care, was instead put under forced isolation[66]. A specific agreement had been adopted between the government and a Dutch rehabilitation centre to forcibly place homeless persons who cannot isolate themselves[67], while there was no protocol in place for other COVID-19 patients.

Lesbian, Gay, Bisexual, Trans, and Intersex People with Disabilities

Since the pandemic outbreak, the organisations ILGA-Europe[68] and Transgender Europe (TGEU)[69] have been reporting that the LGBTI+ community is, and will continue to be, disproportionately affected by COVID-19. Lesbians, Gays, Bisexual, Trans and Intersex persons are being negatively impacted by the virus itself, the healthcare system, and healthcare providers. When accessing healthcare, they face barriers which are increasing during the crisis. This impact is being felt most severely by the most marginalised LGBTI+ population.

In times of health crisis and care rationing, LGBTI+ people, and particularly trans people with disabilities, are being specifically targeted by triage policies. They are being denied life-saving care and face difficulties in receiving disability support, in addition to the already major struggles trans communities face with general and trans-related healthcare access. Cuts in care provision combined with the discrimination most trans people face while trying to access healthcare is seriously impacting their health and wellbeing. For

instance, trans persons with disabilities may have faced difficulties in receiving disability support and trans-related care such as gender-affirming hormones and up-to-date prescriptions. The fact that gender affirming medical and surgical procedures have been put on indefinite hold may also have seriously impacted the health and wellbeing of trans people[70].

In addition, Lesbians, Gays, Bisexual, and Trans persons have seen an increase in domestic violence. Lockdown has condemned LGBT+ people to live in close proximity with sometimes homophobic or transphobic relatives. LGBT+ persons with disabilities were at higher risk to face both homophobic/transphobic and disability specific violence. LGBT+ people who have not told their families yet about their sexual orientation or gender identity may have been experiencing mental health difficulties during lockdown[71].

Older persons with disabilities

Older persons remain one of the groups most severely affected by the pandemic, and face increased social isolation, loneliness, and ageist attitudes.

The United Nations highlighted that “COVID-19 has exacerbated global economic inequalities and exposed existing inequalities that affect older persons, especially older women and older persons with disabilities. This includes inadequate access to essential goods and basic services, limited social protection services, and widespread age discrimination”[72].

Europe has the oldest population of all world regions. In 2019, more than one fifth (20.3%) of the EU-27 population was aged 65 and over[73]. Disability is correlated to age and persons with disabilities are over-represented in the population category that is 60 years old and over[74]. In April 2020, more than 95% of the people who had reportedly died of COVID-19 in Europe were over age 60, and over half of them among people aged 80 years or older[75]. There is also clear evidence that a large proportion of infections and deaths have occurred in residential care for older people and institutions and closed settings for persons with disabilities.

Deaths in residential care

The UN Secretary General reported that the fatality rates for those over 80 years of age is 5 times the global average. The World Health Organisation indicated that half of the deaths related to COVID-19 in Europe have so far occurred in long-term care facilities, in particular in care homes for older persons[76]. The lack of comprehensive and reliable data on people in residential care makes the monitoring of their human rights, health and wellbeing in times of crisis even harder. All these elements combined contribute to this alarming death rate in residental care.

Gaps in continuity of health care, medical treatment, and support services

During the pandemic peak and lockdown, continuity of health services, care and medical treatment could not be ensured due to constrained resources and years of reduced budgets allocated to the health and social sector. The unavailability of personal protective equipment was an additional difficulty on the already long list of challenges faced by health and social care staff. This has forced health and emergency services to establish triage procedures, according to which age and disability were initially thought of as criterion to determine individual vulnerabilities, diagnosis, and/or treatment options. This was one of the most obvious and shocking breaches of the right to live for older people and persons with disabilities. It has certainly disproportionately impacted older persons with disabilities in getting equal access to health care since they combine both criteria. A particularly impacted group are people with dementia. As underlined by the EU Agency for Fundamental Rights, disrupted or curtailed services had a strong impact on the mental and physical wellbeing of people living with Dementia. The Alzheimer Society of Finland, for example, underlined that reducing basic services for people with dementia impairs their ability to conduct their daily lives[77].

Violence, neglect, and abuse

According to WHO estimates, 1 in 6 people aged over 60 suffers from abuse[78]. That means nearly 141 million people globally. This number might be much higher as abuse of older people is a hidden and underreported human rights violation. As is indicated in the section on

Girls and Women with disabilities, reporting for domestic and sexual violence went up dramatically during the lockdown. Older persons with disabilities, especially older women with disabilities, were trapped at home with their persecutors and have suffered from a lack of accessible reporting through hotlines and other online means.

Ageism

Age discrimination is called ageism and some of the most severe manifestations took place since the covid-19 outbreak.

Testimony: older hard of hearing person from France

"During COVID-19 and especially the lockdown, it is the first time I felt my age was an issue. Hearing all day long that you are an "old chap" or an "old companion", or more impolitely that you are an "elderly in danger" when going out from your home is quite a negative and rather fragilising experience, in terms of disrespect."

Numerous ageist comments were seen in both traditional and social media. Negative portraying of older people, describing them as frail, passive, and even a burden to society, has happened. For example, a Belgian economist suggested to impose a corona tax on older persons "because younger people are doing sacrifices for them" in the current crisis[79].

Another striking sign of ageism concerned restrictions for older people to go outside of their home on the single criteria of age. This sometimes applied to persons with disabilities as well. During the first wave of the virus several countries used age as a factor to impose confinement[80]. For instance, Ireland[81] and Sweden[82] requested people aged over 70 to stay at home. In European countries outside of the EU, fines were established. In Bosnia and Herzegovina, for several weeks, people over 65 were not allowed to go outside, with no exceptions for grocery shopping, pharmacy visits, or even taking out the garbage. Over 200 older people were fined. On April 3rd, the government revised the rule to allow older people to go out between 7 a.m. and noon, Monday through Friday[83]. Some older people

and persons with disabilities reported being kicked out, sometimes violently, from grocery shops because they did not respect their dedicated morning hours, even though this was not a convenient time for them[84].

Prisoners with disabilities

Before COVID-19, prisoners with disabilities were already at a higher risk of human rights violations, often living in degrading conditions where their rights were denied. Violations include unsuitability of prison cells, inaccessibility of common areas, lack of appropriate support, and excessive use of immobilisation or overmedication[85]. While there is almost no data regarding the population of prisoners with disabilities, the few numbers available are striking. In France, it was established that, in 2006, detainees with disabilities accounted for some 6% of the prison population. In the United Kingdom in 2008, between 20% and 30% of offenders had been identified with learning disabilities, and in 2016, approximately 400 Deaf or hard of hearing detainees were identified[86].

Overcrowding and inhumane conditions in prisons made them another hotspot of the COVID-19 crisis. A briefing from the European Parliamentary Research Service on COVID-19 and prisons[87] points out that EU Member States adopted measures to suspend all visits and activities to limit contact among detainees, and with the outside world. They also sought to limit entries and increase exits, for instance by using alternatives to detention[88] or postponing the execution of sentences. However, at least half the Member States did not seek alternatives to detention and little information is available on measures taken by prisons to address the situation of prisoners with disabilities.

The website of the European Organisation of Prison and Correctional Services (Europris)[89], only includes information on COVID-19 measures for prisoners with disabilities in Albania and Ireland[90]. EDF's contact with European national prison administrations revealed that in some countries no preventive measures for prisoners with disabilities had been adopted (Lithuania, Luxembourg), while in others, specific measures had been put in place (Denmark, Latvia, Slovakia, Spain and Sweden), including provisions of information in Braille, Easy to Understand, and pictograms, and cooperation with organisations of persons with disabilities[91].

Racialised persons with disabilities

Because most European countries do not collect data on race, ethnicity, and disability, it is difficult to have detailed information on how COVID-19 affected racialised persons with disabilities in Europe.

Data available in the United Kingdom (UK) shows that, although disability may vary by ethnicity, numbers remain high, with 25% of Black/African adults, and 10% of Asian adults, in the UK being persons with disabilities[92]. Research has also found that persons with disabilities from African or Black British ethnic backgrounds report the highest numbers of barriers and exclusion in society, while adults from white ethnic backgrounds report the lowest[93]. COVID-19 made things worse.

The pandemic has exacerbated structural inequalities and racism, putting racialised people at a higher risk of becoming ill and suffering more strongly the socio-economic impact of the crisis. In the UK an investigation was launched[94] after data revealed that people from Black, Asian, and ethnic minority background were up to twice as likely to die from COVID-19 than people of white British ethnicity[95].

Cases collected by the European Network Against Racism have highlighted multiple issues faced by racialised persons in Europe, including[96]:

- Denial of access to healthcare
- Lack of access to protective measures at work during the confinement period.
- Lack of access to alternative housing following confinement measures
- Denial of access to basic services (such as water and electricity) during the confinement period
- Police abuse
- Racist speech online or offline, or racist violence

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A report from Amnesty International illustrates how lockdown measures have exposed racial bias and discrimination within the police in Europe[97]. For instance, in Seine Saint Denis, in France, the number of fines for breaching the lockdown was 3 times higher in one of the poorest areas, where most inhabitants are Black or of North African origin, than in the rest of the country (despite local authorities stating that respect for measures was similar to other areas). In Nice, another French city, 9 predominantly working class and minority ethnic neighbourhoods were subjected to longer overnight curfews than the rest of the city. There was also an increase in reports of police brutality, with numerous videos showing excess use of force by the police.

Racialised persons with psychosocial disabilities have been at an increased risk of involuntary psychiatric treatment and detention during the crisis. Previous evidence has shown that they were at a higher risk of coercion prior to the crisis[98], and that the number of involuntary placements in psychiatry increased since the beginning of the crisis.

Roma with disabilities

While there is no accurate data on the number of Roma with disabilities, a 2016 study estimates that 15% of the Roma population are persons with disabilities, meaning that there would be more than 1.6 million Roma with disabilities in the EU and EU enlargement countries (Albania, Montenegro, North Macedonia, Serbia, and Turkey)[99]. Roma with disabilities experience even greater isolation, less access to inclusive education and more severe poverty. During COVID-19, their situation has been even more critical.

A report published by the EU Fundamental Rights Agency in September 2020 highlights a multitude of issues including discriminatory lockdown measures targeting Roma communities, lack of access to education (due to lack of electricity, internet, and IT equipment), employment support measures excluding informal and seasonal workers, lack of adequate access to housing, food,

and other basic needs, and poor access to healthcare services[100]. Roma with disabilities seem to not have been considered at all in the response to the pandemic.

Refugees and asylum seekers with disabilities

Situation at the borders and asylum procedure

Asylum seekers with disabilities making their way to Europe have been stopped. The EU Agency for Fundamental Rights reported that non-governmental organisations had to suspend their search and rescue operations at sea to comply with emergency legislation. Italy, Malta, and Cyprus closed their ports for most boats. There were also media reports of Cypriot authorities pushing back a boat with 175 Syrians, including 69 children[101].

In addition, due to the pandemic, many countries suspended asylum procedures for asylum seekers applying from abroad, or already in their country. No exception seems to have been made for asylum seekers with disabilities, including women, unaccompanied minors, and children with disabilities[102].

While some countries also suspended the transfers of asylum seekers whose refugee status was refused, others such as France, Belgium, and the Netherlands continued to carry out forced return[103]. Here again, it is not clear whether exceptions were made for asylum seekers with disabilities.

Situation in reception centres

Because of limited access to water and sanitation, overcrowded camps, and lack of accessible information on COVID-19, refugees and asylum seekers with disabilities were put at a very high risk to contracting the virus. Prior to the crisis, Human Rights Watch documented that due to inaccessibility of toilets, washbasins, and showers in Greek refugee camps, some persons with disabilities had to crawl to toilets and showers or wash themselves in the sea[104]. Other organisations have also reported the deplorable conditions in reception centres in Cyprus, Italy, and Malta, and in informal camps in France, stressing that they make it impossible to prevent infection[105].

On 8th of September, a fire in Greece's Moria camp left nearly 13,000 adults and children without shelter or access to basic services. The

inhabitants waited for long periods in the street.[106] According to the Greek Council for Refugees and Oxfam, the living conditions in the new camp are even worse than in Moria, with little or no running water, no sewage management or treatment, limited health facilities, and woefully inadequate shelter[107].

Situation outside asylum and reception centres

For asylum seekers and refugees living in host countries, the situation has also been difficult due to poverty, lack of accessibility, lack of personal protective equipment, and lack of targeted support. The testimony below gives an overview of issues that have been faced.

Testimony: Dickson Tarnongo, Asylum seeker with disabilities in the United Kingdom[108]

"As an asylum seeker with a disability, I am of the opinion that people like myself are very vulnerable and more exposed to COVID-19 when compared with other people and groups in the UK due to poverty and lack. However, little is heard or reported about this vulnerable segment of British society during these challenging times. The voices of asylum seekers with disabilities are seldom heard, yet the risk we face is significant. Our lifestyles are often characterised by poverty as we have no recourse to public funds, and we are therefore unable, or struggle, to access equipment and products that can make it easier for us to adhere to good hygienic practices.

As an asylum seeker with a disability, I normally have no money to take a taxi – and certainly not enough to buy a car – so that I can be less exposed to the virus when compared to using public transport.

People such as myself who use a wheelchair face very particular problems. Instead of the cheap disposable gloves others use, I have to use strong and expensive "Rigger" gloves that I have to constantly change and carefully discard after every single use – since my hands are my legs. […] The funds needed for a disabled asylum seeker to protect themselves from COVID-19 are beyond their means."[109]

Women caring for persons with disabilities

Women caring for one or several persons with disabilities were particularly affected by the COVID-19 crisis.

Because of the disruption of schools, day care, and social services during and after the lockdown, women had to take on additional care responsibilities, often without specific support from the government. While men also had to step in, data shows that caring responsibilities more often fall on women[110], who are also more likely to be the sole carer of one or several children with disabilities[111].

Before COVID-19, already almost half of single mothers were at risk of poverty or social exclusion[112]. This is even higher for women caring for children or other relatives with disabilities, who, when formal long-term care services are not available, must withdraw from the labour market to become full-time carers[113].

In most European countries, schools and social services closed during the lockdown. They were not considered as essential services, and women caring for a person with disabilities often had to become full-time carers. Women whose children were in institutions had to make the hard choice between leaving them there, or becoming a full-time carer, once again with no support. While several countries put special leaves for parents in place, and even if they were extended to carers of persons with disabilities, many carers were on the edge of burnouts[114].

Testimony: Foteini Zafeiropoulou, mother of an adult with high support needs from Greece – member of EDF Women's Committee

"Regarding my experience, as a mother of an adult with high support needs during the period of the first lockdown in spring, the most challenging thing was the change in his/our routine. As every other family with a member with autism and intellectual disability, we had our daily routine. Activities in a specialised community-based center, training and entertainment activities with peers, until early afternoon, shopping afterwards, often to the movies (my son loves movies), sometimes swimming or other sports activities, etc. Everything was dramatically different during that period, because everything was closed. We had to create a new routine, including interesting things, attractive activities that could take place in an apartment and the company of mom and dad exclusively. This is exactly what we did. A little bit of exercise watching videos of indoors work out, moving all furniture in order to have more space to exercise, movies at home with popcorn and soda to look like cinema, a few hours at the balcony, planting and watering flowers or having some tea, pretending that we were at a cafe, playing video games and surfing in the internet looking for funny videos on YouTube, do some cooking together and so on. All these were put in a timetable to help him predict how his day was going to be. At least we managed to keep him calm enough. Of course I was exhausted but compared with what other families experienced (ie self- injuries, tantrums, aggressiveness), my case, to be occupied 24/7 giving my son the full attention he claimed or demanded, was a good one!

Fortunately, during the present [second] lockdown, because of the intervention of the National Confederation of Disabled People at least community- based training centers, day care centers, as well as special schools remain open.

At this point I would like to add the testimony of a single mother, who had to leave her teenage son in an institution, because she was a victim of domestic violence and institution seemed to be the only solution at that time for her child. She calls me almost every day crying because she is not allowed to visit for nine months, and she has not seen her son since March. We have also received a few emails in my organisation concerning this issue. Many family members that cannot visit their relatives in residential homes or institutions."

Chapter 5: European Union's response, responsibilities, and shortcomings

The European Union (EU) has important obligations to protect the rights of persons with disabilities, particularly since its ratification of the Convention of the Rights of Persons with Disabilities (CRPD) in 2010. Even before ratification of the CRPD, the EU included the rights of persons with disabilities in its Treaties and adopted disability strategies[115]. As the CRPD came into force in the EU[116], the EU adopted a European Disability Strategy (2010-2020)[117] that set out the 10-year priorities for disability rights at the EU level.

These obligations under the CRPD and the strategy, did not, however, convert into a disability-inclusive response to the COVID-19 pandemic. With some exceptions, EU institutions and agencies largely did not take the necessary measures to ensure their crisis response was inclusive of persons with disabilities.

Overview of the EU's COVID-19 response

The EU's crisis response involves a range of institutions, with different roles and responsibilities. Importantly, the EU is not responsible for all COVID-19 actions- healthcare policy itself is a national issue. However, COVID-19 has shown us the shortcomings of a purely national approach in a pandemic.

In this chapter, we focus on COVID-19 related issues that are the direct responsibility of the EU institutions. We pay attention to the measures taken by its main institutions – the Council of the EU, the European Commission, and the European Parliament – and we highlight some EU agencies whose responses were most central to the pandemic response, such as the European Centre for Disease Control and Prevention (ECDC), the EU agency for Fundamental Rights (FRA), Eurofound and others, including the Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG-ECHO).

In March, EU leaders decided in the Council that the EU's response to the COVID-19 crisis would focus on four priority areas[118]:

- Limiting the spread of the virus.
- Ensuring the provision of medical equipment.
- Promoting research for treatments and vaccines.
- Supporting jobs, businesses, and the economy.

Disability issues were relevant in all four priority areas of EU response, yet there was little or no attention to disability rights in measures adopted by the Council and the European Commission.

On March 2nd, an EU COVID-19 response team was established[119] including President Ursula von der Leyen, Commissioner Janez Lenarčič (in charge of crisis management), Commissioner Stella Kyriakides (in charge of all health issues), Commissioner Ylva Johansson (in charge of border-related issues), Commissioner Adina Vălean (in charge of mobility), and Commissioner Paolo Gentiloni (in charge of macroeconomic aspects). Despite the evidence of how inequality and social exclusion were factors reinforcing the impact of COVID-19 on people, neither the Commissioner for Equality, Helena Dalli, nor Commissioner Schmit, responsible for employment and social inclusion, were included in this team.

Consultation of organisations of persons with disabilities

During the first months of the crisis there were no formal consultation meetings initiated by the European Commission, despite EDF sending a range of advocacy letters explaining the impact on persons with disabilities and requesting meetings to discuss how to ensure the response was inclusive. A structured dialogue is not in place, so consultations and discussions were reactive and ad hoc.

Over the course of 2020, EDF has raised a range of issues to the European Commission in the form of formal letters and received a number of responses to our concerns. It was also possible to raise issues related to COVID-19 and the crisis at a series of consultation initiatives by the Equality Commissioner, as she engaged with civil society partners in dialogue about the next European Disability Strategy. DPOs also had the chance to discuss and raise concerns at the Disability High Level group in May 2020, and the European Day of Persons with Disabilities online conference in December 2020.

The European Commission, through its Citizens, Equality, Rights, and Values (REC) Programme provides public funding to DPOs and other disability organisations for their advocacy work at the EU level, and this has enabled DPOs to organise, advocate, and support their members throughout COVID-19. The next EU budget will continue this trend through the Justice, Rights and Values Fund.

The European Parliament has most substantially taken initiatives to include persons with disabilities. At various points the Parliament consulted with persons with disabilities in different ways or responded to the concerns raised by organisations of persons with disabilities. These include:

- Meeting of the Parliament's Disability Intergroup to discuss the impact of the pandemic on persons with disabilities on April 30th[120]. The Commissioner for Equality, EDF, and several EDF members were present at the meeting. This was the first high level discussion on the impact of COVID-19 on persons with disabilities.
- Joint letter signed by 47 Members of the European Parliament calling the Commission and the Council to take immediate actions to mobilise Coronavirus Response Investment Initiative and EU funds to guarantee the continuity of care and support services in Europe during COVID-19 pandemic[121] on 8th April.
- Adoption of a resolution on an "EU coordinated action to combat the COVID-19 pandemic and its consequences" on 17th April[122] in which the demands of the disability movement were included[123].
- Adoption of a resolution on the rights of persons with intellectual disabilities and their families in the COVID-19 crisis on 8th July[124]. This recognises, and comes after discussion of, a petition from Inclusion Europe[125] about persons with intellectual disabilities on May 19th[126]. The resolution also calls on the Commission "to consult and involve persons with disabilities and their representative organisations from the outset when adopting measures responding to a future crisis".
- Statement by a group of 88 members of the Parliament[127] in response to the joint-letter from EDF and others to investigate the impact of COVID-19 on long-term care facilities[128]. This was

followed up by a joint public hearing of the Employment and Social Affairs, and the Civil Liberties committee on January 28th 2021[129].

Public health announcements

At the beginning of the pandemic, the EU leaders made a series of public and high-level statements to Europeans about the pandemic and failed to ensure these statements were accessible to persons with disabilities. President von der Leyen addressed the EU without interpretation in International Sign or captioning, and without Easy to Read information supplied.

This has been rectified after advocacy from the disability community[130]. The European Commission produced an information video on "5 ways to prevent the spread", which used international sign[131] on 13th March 2020. The first accessible video[132] of a statement of the President of the European Commission was published on the 31st of March 2020. However, the Disability Unit webpage, as of October 2020, does not mention any activities, reports, or news items relating to COVID-19 response and persons with disabilities[133].

On 8th April, the Commission published a recommendation for the development of mobile applications to tackle the COVID-19 pandemic, stressing the support for accessibility requirements for persons with disabilities[134]. The EU COVID 19 webpage also presents information in a clear and readble way.

Access to health care, testing and vaccination

The EU has limited competence to act in the field of healthcare, where it can only support the actions of the Member States and encourage cooperation[135]. The European Commission coordinated actions of Member States and facilitated the supply of protective and medical equipment across Europe. So far, the measures have not paid specific attention to persons with disabilities[136].

The European Centre for Disease Prevention and Control (ECDC), an EU agency aimed at strengthening Europe's defences against infectious diseases, played an important role in monitoring the spread of COVID-19 and giving guidance to Member States. Despite its important role, the ECDC does not appear to have a focal point on

disability and did not sufficiently consult organisations of persons with disabilities during the COVID-19 crisis[137].

The regular monitoring of COVID-19 in Europe, by the ECDC, which includes COVID-19 data, is disaggregated by age and gender, but not by disability.

The first guidance of the ECDC including persons with disabilities in the response to the COVID-19 pandemic concerned the provision of support for medically and socially vulnerable populations published in July 2020[138]. Other documents do not systematically consider persons with disabilities. For example, the fourth update to the "Infection prevention and control and preparedness for COVID-19 in healthcare settings" does not mention persons with disabilities even though it was released on the same date as the guidance which includes assessment of disability[139].

There also has been a serious delay in the ECDC recognising the urgency of the situation in closed settings, such as institutions. For example, an ECDC report in the first half of April recognised the issue but did not raise attention to the issue to the extent it could have[140]. At the same time, data from European countries was already showing that deaths in long-term care facilities made up for half of the deaths related to COVID-19[141]. Over a month later, ECDC published guidance with much more substantial advice on disease surveillance at long-term care facilities[142].

The European Union has not been explicit enough in its inclusion of persons with disabilities in the COVID-19 roll-out strategy. The communication to the European Parliament and Council on 'Preparedness for COVID-19 vaccination strategies and vaccine deployment' adopted on 15th October made no explicit mention of persons with disabilities[143]. On October 28th, the Commission's recommendation on testing also completely excludes persons with disabilities[144].

The European Disability Forum addressed leaders of the EU institutions on this issue[145] and received a detailed reply from the Commissioners for Health and Equality[146]. In the reply, the Commissioners highlight the importance to protect persons with disabilities from infection and ensure they have equal access to all necessary procedures. They indicated the role of the EU Member

States in relation to the organisation and delivery of health care, vaccination, and testing strategies. They noted that public health matters are within the competence of Member States and national governments decide on the specific measures and strategies based on each country's national epidemiological and social situation.

Equality and non-discrimination

Equality and non-discrimination have not been comprehensively considered in the response to COVID-19 by the European Commission and the European Council. In some specific instances, recommendations have indirectly discriminated some persons with disabilities[147]. Additional issues further discussed in this chapter, such as the lack of accessibility in public communication and failure to provide reasonable accommodation by public administrations, are other examples of discrimination.

The Fundamental Rights Agency of the European Union (FRA) played an important role in monitoring the human rights response to the crisis. The agency responded promptly to concerns raised by EDF in April that the information provided in its bulletins on the human rights implications of the COVID-19 crisis was limited and not based on involvement of persons with disabilities[148]. Since then, more information on the situation and human rights violations faced by persons with disabilities are included in their bulletins. However, the bulletins only investigate measures adopted by Member States. There is no information on the impact the response of the EU had on human rights.

Gender equality and women's rights

In June 2020, the European Commission published a factsheet on the impact of the pandemic on gender equality[149]. Beyond the impact on health, it recognises that the crisis has an important impact on gender equality, and that existing inequalities, including based on disability, are exacerbated. The European Institute for Gender Equality (EIGE) also included persons with disabilities as "people in vulnerable situations"[150] on its webpage on COVID-19 and gender equality[151], noting that women with disabilities are more at risk of violence and face barriers in accessing shelters for victims.

Regarding domestic violence, the EIGE published a list of helplines in all EU Member States that remain open during the pandemic[152]. The document is not accessible for users of screen readers and does not specify whether the helplines are accessible to all women with disabilities, for instance by allowing text messages. The Institute is also conducting a study on the implications of COVID-19 for women victims of intimate partner violence, but it is not clear whether it will include information on women with disabilities[153].

Allocation of EU funding and Economic Recovery

The way EU funding is allocated changed quite drastically because of the COVID-19 pandemic. There have been changes both to the rules for using funding in the funding period 2014-2020, and changes to the way funding will be planned for the 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.

Starting with the changes made to the 2014-2020 financial framework, we have seen significant changes to the rules for how Structural Investment Funds and Cohesion Funds can be used by the Member States. These are EU funds intended to redistribute wealth throughout the EU and invest in a harmonious development of the Union that minimises inequalities between different Member States and regions. The main change is the flexibility the Member States have been given regarding how and where they invest the EU funds designated to them. This exceptional flexibility was introduced through the Coronavirus Response Investment Initiative, and the Coronavirus Response Investment Initiative Plus. The new flexibility of Structural investment Funds Cohesion Funds sees some major short-term changes, including:

- Co-financing up to 100% upon Member States' requests
- Extended deadlines for the managing authorities to submit the annual implementation report
- Flexibility regarding the region within each Member State in which the funds are used
- Flexibility to transfer a certain amount of money between different funds with different objectives, for example between the

European Social Fund, which invests more in social inclusion and human potential, and the European Regional Development Fund, which typically invests more in infrastructure

- A simplified procedure for re-programming so Member States can modify the programmes immediately in line with newly emerging needs without needing the Commission's approval
- New eligibility for Structural Investment Funds to cover the working capital in Small/Medium Enterprises and support crisis response capacities in public health services
- Focused emergency spending on support for the following target groups: homeless people, persons in institutions, and segregated Roma ghetto's in Eastern Europe.
- Support for digital/distance learning.

Then there is the extra money that has been made available to the Member States to help with recovery from the COVID-19 crisis. This new pot of money is called "Next Generation EU". It comes to a total of €750 billion. The Member States came to an agreement in July 2020 that €390 billion of this total amount should be given in the form of grants and €360 billion in the form of loans. Most of this extra money, €650 billion to be precise, will go towards the new Recovery and Resilience Facility. This is a mechanism designed to "provide large-scale financial support to reforms and investments undertaken by Member States, with the aim of mitigating the economic and social impact of the coronavirus pandemic and of making EU economies more sustainable, resilient and better prepared for the challenges posed by the green and digital transitions." We also see €47.5 billion of this money, entirely in the form of grants, going towards boosting Cohesion Policy in the form of the REACT-EU initiative. REACT-EU is the name of the money from Next Generation EU that goes directly to boosting Cohesion Policy investment. It is the investment through REACT-EU that is most likely to directly reach persons with disabilities, through the European Social Fund and the Regional Development Fund. Both funds are instrumental in investing in accessible infrastructure and technology, supporting employment and education, and bringing persons with disabilities out of institutions in favour of community-based settings.

The idea, using the language of the European institutions, is that the investment from Next Generation EU, and all the separate initiatives that form part of it, should be “frontloaded”. This means the idea is to spend the money soon, no later than two years from now, to help stop the financial crisis emerging from the pandemic, speed up necessary national reforms, and ensure a swift economic recovery.

It will be especially important that the investment of EU funds to ensure economic recovery from the COVID-19 crisis, focus on the impact it has had on women with disabilities. Even before the pandemic, many women with disabilities were shown to have fewer financial resources, face higher unemployment rates, and are at a much higher risk of poverty. The European Institute of Gender Equality, concerned about the economic impact of the COVID-19 pandemic, recognised that women in general face a higher economic hardship[154].

Data collection and research

Several bodies of the European Union oversee research and data collection. Except for the Academic Network of European Disability Experts[155], they were all active during the pandemic, yet did not comprehensively collect data and other information on persons with disabilities.

Eurostat

COVID-19 had a direct impact on the ability of Eurostat and national statistics institutes to collect data. In an effort to ensure that this process of data collection continues, and that the reality as of March 2020 is reflected in EU statistics, Eurostat and national statistics institutes have moved from in-person data collection to phone and on-line interviews, and have introduced measures to facilitate the submission of data by businesses[156]. However, there has been no mention of adapting the way data collection is done in order to better understand the impact of the pandemic on at-risk groups, such as persons with disabilities. No mention has been made, for example, of collecting data disaggregated by disability.

European Foundation for the Improvement of Living and Working Conditions (Eurofound)

There are important ways disability is included in Eurofound data as well as important gaps. In terms of inclusion, the Eurofound database on COVID-19 policies includes a marker for “Disabled” (as a group of citizens) and “Disabled workers”[157] and a study is anticipated with results on measures that Member States have taken following persons with disabilities in the world of work[158]. However, on the e-survey that the agency conducts on living and working during COVID-19, questions on disability status of respondents were not included[159].

European Centre for Disease Prevention and Control

The European Centre for Disease Prevention and Control has played a key role in collecting and disseminating data and information on COVID-19 in the EU. It has failed to disaggregate this data by disability[160].

Joint Research Centre

The Joint Research Centre COVID-19 Survey did not include any disability-related questions[161]. The data was disaggregated by age and gender. EDF has written on 29th of May to the Director of the Joint Research Centre on this topic and has not received a reply[162]. This is again a missed opportunity by an EU Agency to gather data on the impact of COVID-19 on persons with disabilities.

EU as public administration

The EU’s role as a public administration includes responsibilities towards staff members with disabilities, or those with family members with disabilities, and the inclusive education of students with disabilities at European schools.

EU institutions as employers

In terms of staff members, there appears to have been limited coordination of the necessary accessibility and reasonable accommodation measures[163]. In the European Parliament, there were cases of staff with long-term health conditions, or those with family members at higher risk to COVID-19, not being granted any

accommodation to decrease their risk of exposure[164]. Some of these gaps are related to pre-crisis requirements for permission to telework in the Parliament staff regulations[165]. Further concerns on accessibility and reasonable accommodation were raised in terms of teleworking and return-to-work.

Some staff members with children with disabilities reported to EDF that they had to take full-time annual leave to care for and support their children, with the challenges this has on their psychological wellbeing. They have found it difficult to share confidential information concerning their personal situation and explain their family circumstances in order to be granted accommodations.

In terms of medical insurance, there have been gaps in coverage for COVID-19 and its consequences[166]. Despite calls since March 2020, the Joint Sickness Insurance Scheme (JSIS) that covers the health of all EU staff and their relatives, did not recognise COVID-19 as a serious illness. Only some health consequences of the virus could be considered serious, on a case-by-case basis. This means that not all costs related to the virus, such as testing and first-line medical care, benefited from full reimbursement. In May, the Office for the Administration and Payment of Individual Entitlements of the European Commission decided that hospitalisation linked to the virus would be reimbursed from the first night on. At the time this report was written, the JSIS did not have a COVID-19 strategy.

European Schools

The European Schools are intergovernmental schools principally designed for children of employees of EU institutions. The European Schools Board is made up of representatives of the EU Member States and the European Commission. There have been a range of recommendations made to the European Schools regarding inclusive education in the past years from the European Ombudsman, the CRPD committee recommendations in 2015, and, most recently, in a report published by Human rights Watch and EDF[167]. According to a report published in May 2020, during the 2018-2019 school year, out of a total of 27,176 students[168] 1,993 were receiving intensive support and 2 children with special educational needs were refused admission[169].

The CRPD review in 2015 highlighted the lack of an inclusive education policy in the schools and called for a new inclusive education policy to be adopted, including a non-rejection policy. COVID-19 reminded us of the barriers children with disabilities face in the European Schools system.

European Schools closed in line with measures taken in the countries they were based in. At the start of April, distance-learning for all pupils was announced[170]. During the COVID-19 crisis children with disabilities faced difficulties because the schools did not take sufficient measures to ensure inclusive education.

Reports from parents of children with disabilities suggest that their children faced challenges resulting from the diversity of methods used for distance learning. Online tools for teaching and evaluation were not always accessible. There was also a lack of reasonable accommodation support, and assistance was based on the possibility of a physical visit to the student's home or parents' own initiative.

The EU's role in the world

COVID-19 is a global pandemic that impacted the world in 2020. While the report mainly focuses on the response of the EU and its Member States, it is important to highlight the leading role the EU plays in the world in terms of human rights and diplomacy and as a signatory of the CRPD. This is also important considering EU's role in the research, production and distribution of COVID-19 vaccines. The lack of a fair distribution of vaccine globally risks to impact persons with disabilities in low- and middle-income countries.

International organiations, including the World Health Organisation called for a fairer distribution of vaccine globally[171]. In September 2020, according to Oxfam wealthy nations representing just 13% of the world's population had already bought more than half (51 percent) of the promised doses of leading COVID-19 vaccine candidates[172].

The EU's International response to COVID-19

In the global response by the EU to COVID-19[173], a "Team Europe" package of 38.5 billion euros was launched in April 2020 to support partner countries in the fight against the pandemic[174]. The budget has been mobilised to support the Response Plans of international

organisations, providing immediate humanitarian relief in the most affected countries, organising logistics, supplying healthcare devices, and delivering essential goods, food, and water.

In July 2020, the Commissioner for International Partnerships, launched the Global Monitor of COVID-19's Impact on Democracy and Human Rights[175], which is a partnership between the EU and the International Institute for Democracy and Electoral Assistance (IDEA). The online platform gathers updated information on 162 countries about democracy and human rights, from media freedoms to constitutional checks and balances. There is no specific attention given to the protection against discrimination. For example, in searching this platform, it is not possible to gain knowledge on the impact on women, persons with disabilities, etc. EDF has reached out to the IDEA on this in September, and still, at the date of publishing have had no response.

The EU's action at the UN level

The EU also acted at the UN level, in May 2020, when the EU leaders - Vice Presidents Borrell and Jourova, and Commissioner for Equality, Dalli, supported the Joint Statement on the UN Secretary-General's call for a Disability-inclusive response to COVID-19 – Towards a better future for all[176].

There is evidence of commitment to disability inclusion in international cooperation and humanitarian action: Jutta Urpilainen, European Commissioner for International Partnerships, made a keynote speech at the UN High Level Political Forum in July 2020, in which she highlighted that tackling inequalities facing persons with disabilities was an important element of 'building back better' after the COVID-19 pandemic[177]. In May 2020, Commissioner Urpilainen organised a Civil Society roundtable on the Global Response to COVID-19 in which the disability movement was included. During the meeting, it was highlighted that the situation of groups at risk of vulnerability is particularly difficult and that the crisis is heavily affecting persons with disabilities, children, and women. The participants

referred to the importance of involvement and support of local civil society organisations and DPOs in dialogue, consultations, and implementation, but no concrete actions were agreed.

The EU's work on international cooperation and development

In terms of projects in the global south, several EU projects have adapted their response to COVID-19, with the inclusion of persons with disabilities taken into consideration. The projects are difficult to find on EU institutions' websites, unfortunately, but nonetheless, they are ongoing with the EU as one of the donors or as the main donor. During the research for this report, EDF identified disability inclusive COVID-19 projects in Burkina Faso, Ecuador, Ethiopia, Nigeria, Mongolia, Paraguay, Sudan, Timor-Leste, and Zambia, and these are presented on the EDF website. The projects cover topics including public health, water and sanitation, access to finance, food security, gender-based violence, and inclusive emergency response.

Chapter 6: National responses and shortcomings

This chapter examines the COVID-19 response at the national level in Europe. EDF took a snapshot of the national responses, and 32 country response summaries are provided on our website. Most of the analysis is based on information gathered through August and September 2020. It is based on online resources and input from EDF members, and brings together data from the start of the crisis to the time of writing. The country profiles, which can be read online, will be updated based on input and feedback from EDF members in those countries.

In many countries there is extremely limited or no data on persons with disabilities. Data on disability was not gathered before this year, and the existing gap became magnified during the pandemic. In national statistics, health information systems, mortality information, or social surveys, information was often not gathered on persons with disability during the crisis.

Because of this lack of data, the individual experience of persons with disabilities gained even more importance. Information from EDF members and ad hoc surveys gave insight into the situation at national and local levels.

This chapter covers the following key areas of national response:

- Public announcements and accessibility of communication
- Emergency, lockdown, and confinement
- Involvement of persons with disabilities
- Health care
- Institutions and other closed settings
- Social protection
- Education
- Employment

Impact of COVID-19 on persons with disabilities

Existing data shows the awful consequences faced by persons with disabilities during this crisis in loss of life and economic damage.

Persons with disabilities and COVID-19 cases and deaths

Where data is available on persons with disabilities' death rates from coronavirus, it shows that they are more likely to die of COVID-19 than persons without disabilities. This is shown in **England** and **Wales** where data of COVID-19 has been disaggregated by disability. Other countries do not publish, and mostly did not gather, the disability status of persons who died from COVID-19.

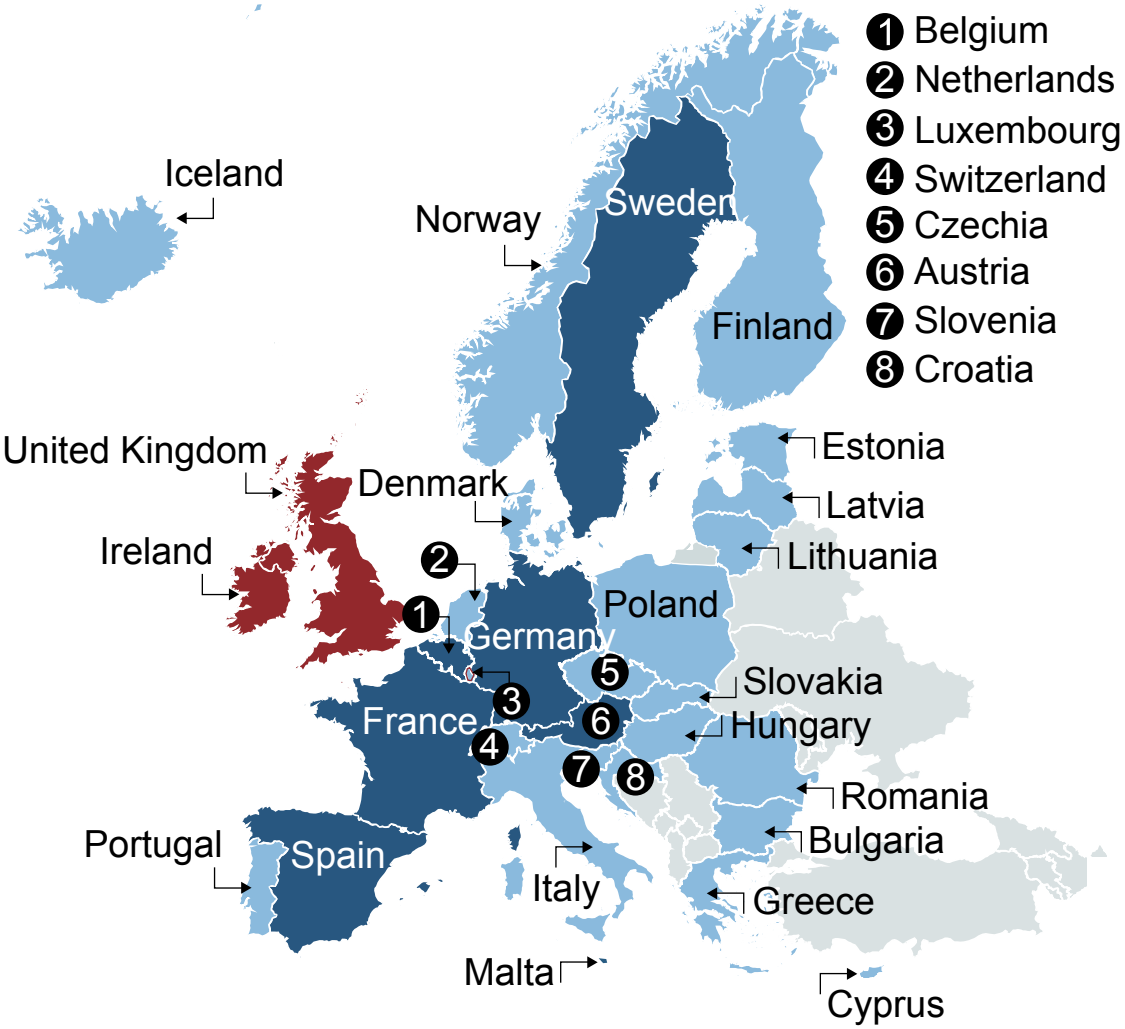
The data from **England** and **Wales** shows a devastating death rate for persons with disabilities. A total of 27,534 persons with disabilities died between March and July, of a total of 46,314 deaths. In this analysis, persons with disabilities are 16% of the study population but made up 59% of all deaths involving COVID-19 between March and mid-July 2020. After adjusting for age, and other demographic characteristics, women with disabilities were 2.4 times more likely to die from COVID-19 than women without disabilities, and men with disabilities 2 times more likely to die than men without disabilities. These figures were gathered by cross-referencing the mortality information with disability status in the census of 2011[178].

Data from **Ireland** and **Spain** shows that in terms of COVID-19 cases persons with disabilities are overrepresented. There is no data on comparable death rates for either of these countries. In **Ireland**, the confirmed incident standardised rate of COVID-19 for persons with disabilities is 548 for every 100,000 people, while for persons without disabilities it is 516[179]. In **Spain**, a study was conducted on the presence of antibodies to see who had had COVID-19. There were 3,000 persons with disabilities in the study, 5% of the total sample. The prevalence of antibodies among persons with disabilities ranged between 3.6% and 5.5%, compared to 5.2% for the population without disabilities[180].

Some countries gathered data on deaths of persons with disabilities in a more localised way. For instance, in **France**, by the end of April, 270 persons with disabilities had died in institutions for adults with disabilities, a mortality rate of 180 per 100,000 people[181]. **Ireland** shows only 16 deaths in residential facilities for persons with disabilities related to COVID-19[182]. Some other countries, including **Belgium**, gathered some information on cases and deaths of persons with disabilities at the level of local government. It shows, for example, less than 50 deaths of persons with disabilities in Walloon and Flemish Regions[183].

For most countries, we do not have data on cases and deaths from COVID-19 for persons with disabilities.

Data collection on persons with disabilities and COVID-19



Disaggregation by disability of key data on COVID-19 cases and deaths: No country

- Some analysis on cases or deaths of persons with disabilities with COVID-19
- Selected information on cases or deaths (for example in institutions)
- Other/unknown

This data on cases and mortality of COVID-19 has been one of the principal tools that countries, organisations and individuals have used to manage and respond to the pandemic. While data is routinely disaggregated by age, gender, and sometimes underlying health condition, it is not done so by disability. This means persons with disabilities are invisible in the tools which are used to respond to the crisis. Invisibility in the data leads to exclusion in response planning and implementation.

The only example of systematic data disaggregation we identified was from **England** and **Wales**. There is no reason to believe the death rates were different elsewhere.

Cases and deaths in institutions and closed-settings

A large proportion of COVID-19 deaths across Europe were in long-term care facilities. In many European countries, the proportion of total deaths of COVID-19 is **30-60% from "long-term care facilities"**[184].

Among these long-term care facilities are facilities dedicated wholly or partially to persons with disabilities. Those facilities dedicated to older persons also include many persons with disabilities due to the increased prevalence of disability with older age and, in some cases, because of a lack of services and support for persons with disabilities to live independently.

Persons with disabilities were exposed to the severest effects of the pandemic and lockdown measures due to institutionalisation.

Social and economic consequences of the COVID-19 crisis

Data shows the economic challenges that persons with disabilities faced during the crisis and their disproportionate impact on persons with disabilities.

- **France**. A survey in early May of 4,400 people showed that 56% of persons with disabilities had financial difficulties connected to confinement compared to 32% of respondents without disabilities[185].
- **United Kingdom**. A weighted sample survey of 6,000 people in June showed that 27% of persons with disabilities are facing

redundancy, rising to 37% for persons whose disabilities have a substantial impact on their activities. This is compared to 17% of the working population[186].

In other areas of life there were also serious challenges faced by persons with disabilities. These include reduced access to services and challenges in mental and physical health. Isolation has had a deep impact on both.

- **Netherlands**. A survey at the start of April of 532 persons with disabilities and people supporting persons with disabilities found 60% of respondents experienced reduced, changed, or no professional support due to the crisis. 45% had deteriorating physical health and 38% had an increase in stress or psychological complaints[187].
- **Portugal**. A survey at the end of April and start of May of 725 people with disabilities and their families and carers found 40% of respondents had cancelled important services or assistance[188].

Domestic violence

The increased prevalence of domestic violence during the COVID-19 crisis have been particularly damaging for persons with disabilities and especially for women with disabilities. For example, in France, reports of domestic violence have increased by 32% during the lockdown[189] and in Cyprus, helplines have received an increase in call of 30%[190]. Although we do not know the proportion of women and girls with disabilities who were victims of violence during the pandemic, the UN Office of the High Commissioner for Human Rights (OHCHR) reported that, globally, women with disabilities, although likely facing higher numbers of domestic violence, were reporting less. This lower reporting can be due to a variety of challenges that pre-existed COVID-19 such as a lack of awareness of their rights, but also lack of support to report, inaccessible helplines, reporting mechanisms and overall support services for victims, including shelters.

Outside of the home, persons with disabilities have also been subject to COVID-19 crisis-related harassment. Some have been refused access to supermarkets, harassed for not wearing masks, or faced other types of hate speech.

National responses to COVID-19 and inclusion of persons with disabilities

Governments' responses to the COVID-19 crisis are characterised by limited understanding and attention to persons with disabilities. Inclusion of persons with disabilities should have been a transversal part of the governments' responses. Unfortunately, the responses in the first half of 2020 did not show this.

In too many cases, governments made little or no acknowledgement of the risks and challenges faced by persons with disabilities. In **Austria**, various groups jointly criticised laws on social distancing for not taking into account the situation of persons with disabilities or older persons[191]. The Irish Human Rights and Equality Commission regretted that the State had not taken action for persons with disabilities from the beginning of the crisis[192]. In **Romania**, the Ombudsman raised an alert in April that the emergency measures did not taken into account persons with disabilities[193]. Even countries with dedicated Ministers for Disability did not appear to better represent persons with disabilities in the response to the crisis.

Of the few countries that took general measures to ensure inclusion in overall crisis response, **Hungary** made an action plan for persons with disabilities during the crisis[194], and the **Netherlands** took measures to prepare one[195].

As we see below, there are specific cases of attention and action for inclusion of persons with disabilities, often as a result of advocacy from disability rights organisations. Throughout the crisis, and continuing today, there are all-too common reversions to medical or paternalistic conceptions of disability that do not follow a rights-based approach.

This section shows how these dynamics play out through key moments in the pandemic.

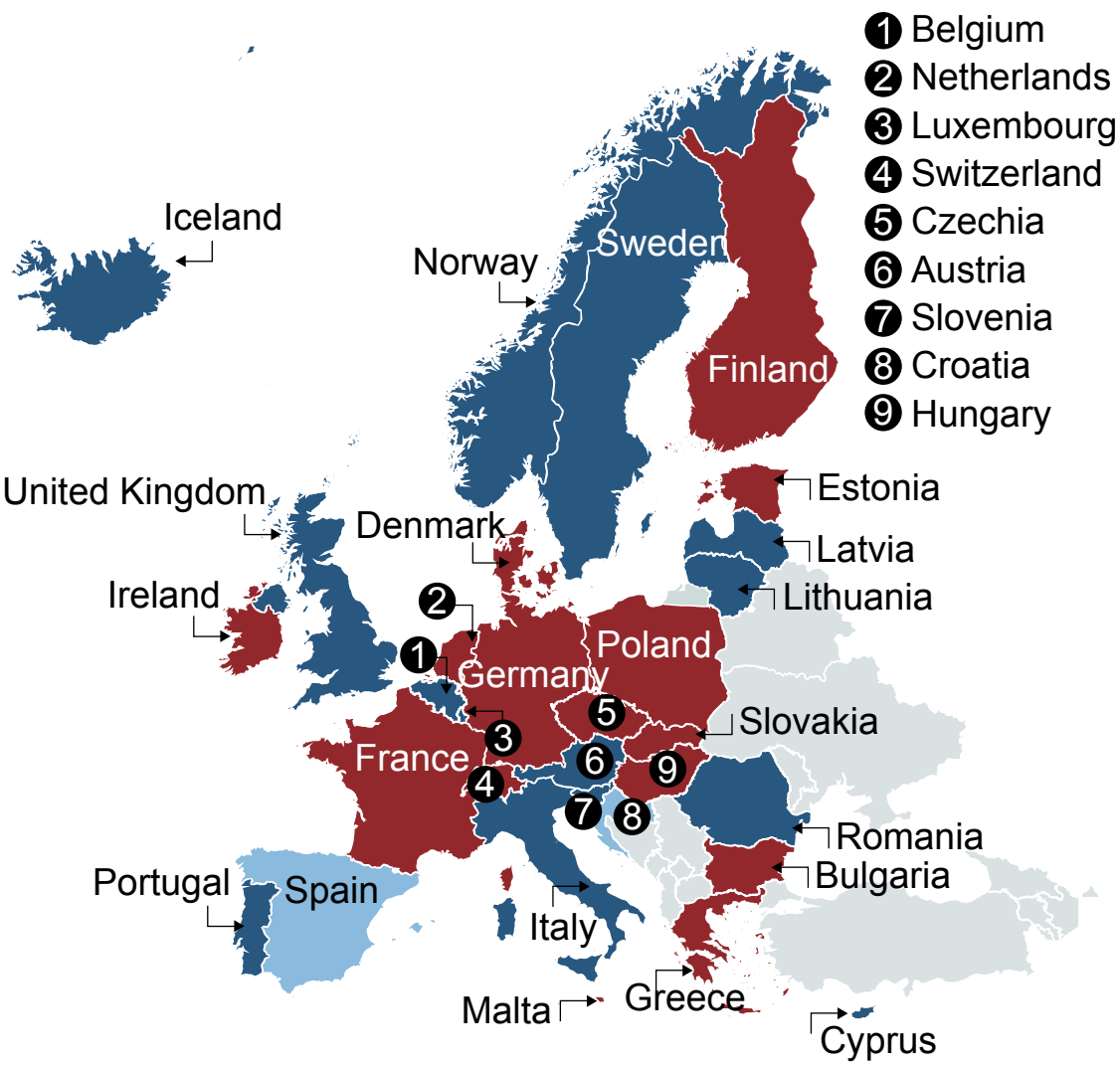
Public announcements and accessibility of communications

Lack of accessibility of important public health announcements and national emergency measures were the first important gaps in national pandemic responses, despite existing EU legislation obliging Member States to ensure accessible emergency information[196], and emergency communications and public warning systems[197], including legislation ensuring the accessibility of public sector websites and mobile applications[198].

Accessibility of important government announcements improved through the pandemic, often as a direct result of advocacy. Sign language was made available in many countries' national announcements on public health and response to the crisis[199]. Other measures were taken to develop accessibility of vital information, including easy-to-read information (often prepared by disability organisations in civil society). Websites and mobile applications related to COVID-19 were made accessible.

- **Italy** issued a decree on urgent digital simplification and innovation that made it mandatory for services of public interests and service providers to make their websites accessible[200], widening the scope of the European legislation on web accessibility.
- **Germany** faced complaints regarding the lack of accessibility of COVID-19 related information and adopted a series of measures including easy-to-read information, email service, fax and helpline, subtitled videos, and videos in German sign language[201].
- In **Spain** the government released a mobile application to tackle the COVID-19 pandemic, and after the disability movement publicly complained and sent comments[202], the application was fixed and is now accessible.

Accessibility of key government communications



Systematic provision of accessible communications: No country

- Made significant provisions of accessible communications
- Limited provision of accessible communications
- Other/unknown

Some new ways were developed to ensure information reached and was accessible to persons with disabilities. Countries, including **France**[203], **Ireland**[204], and **Italy**[205], among others, dedicated online platforms or pages providing specific information for persons with disabilities. Video service helplines for Deaf users were provided in **France**, Poland, and the **United Kingdom**. In France, it was a teleservice to provide assistance and answer questions for Deaf and hard of hearing people[206]; in **Poland**, a video helpline through a partnership with the Polish Association for the Deaf[207]; and in the **United Kingdom**, a video service for those claiming Universal Credit[208]. Some countries, including **Bulgaria**, offered helplines for psychological support[209.] Sometimes these were for the general population, however, the **Bulgaria** helpline was targeted at older persons and persons with disabilities.

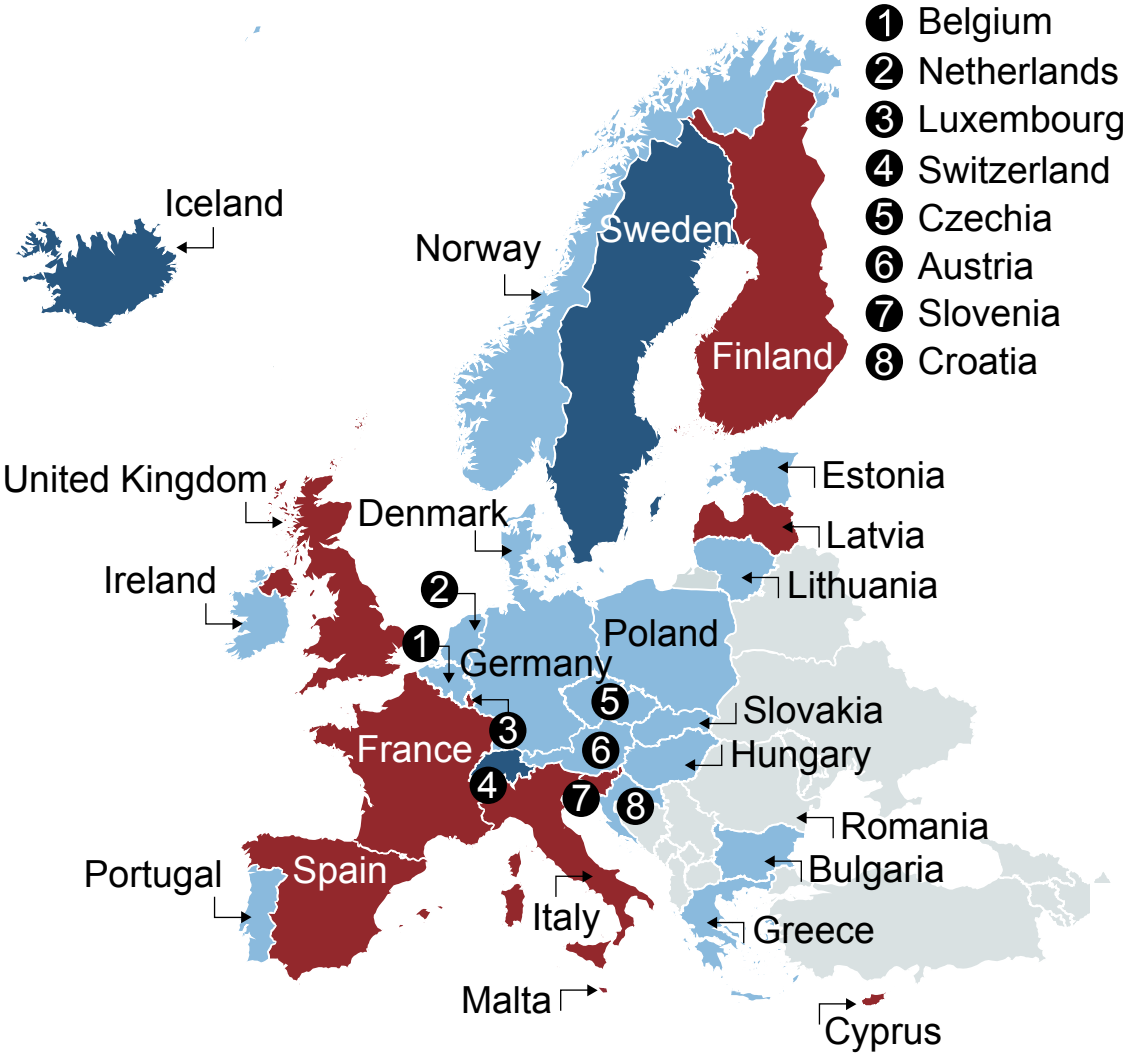
These accessibility measures were often taken in response to advocacy from the disability movement or based on intervention from equality bodies. Accessibility measures were also often not taken consistently across all areas of communication. In some cases, including **Iceland**[210] and **Latvia**[211], provision of accessibility features decreased when the crisis was perceived to have reduced in severity. Many gaps in sign-language provision, availability of captions, accessibility of digital content, lack of easy-to-read materials, and accessibility of helplines remain.

When public health or emergency announcements were made, they usually did not include direct reference to persons with disabilities. Sometimes reference was made through wider categories that might include some persons with disabilities, using labels like “vulnerable” or “at-risk” people. This can create confusion for the public when persons with disabilities have exemptions from certain requirements, such as the requirements on wearing face-coverings. There are some examples of persons with disabilities being mentioned in terms of specifically relating to certain topics, but this does not seem to have been done consistently anywhere.

Emergency, lockdown and confinement

Many governments entered a state of emergency, and/or adopted strict lockdown and confinement measures that reshaped society. In some cases, there were legal or policy changes that explicitly reduced the rights of persons with disabilities; in many cases the general restrictions placed on organisations, people, and movement limited essential services for persons with disabilities. More positively, many countries introduced exceptions to allow continuation of disability-related services, or different restrictions on persons with disabilities, and these became more nuanced as the crisis progressed.

Exceptions for persons with disabilities in lockdown or confinement



- Lockdown with significant exceptions for persons with disabilities
- Lockdown with minor or no exceptions for persons with disabilities

Limited or no lockdown, and significant exceptions/supports for persons with disabilities: No country

- Limited or no lockdown, but minor or no exceptions/supports for persons with disabilities

However, overall, a combination of oversight, neglect, and insufficient response meant persons with disabilities were disproportionately affected irrespective of whether countries adopted stricter lockdown measures or avoided lockdown altogether. As well as the damage that this has caused, there are serious concerns for the future. While many of the more nuanced policies remain in place relating to persons with disabilities, there is reduced or limited support for those that need to continue following stricter shielding as countries open up.

Many countries saw services for persons with disabilities limited or cancelled without replacement. In the **United Kingdom**, the Coronavirus Act allowed the government to reduce the right to support and care, education, and mental health protections[212]. Many countries suspended disability services, including assistance services, special education, day care centres, supported employment facilities, and provision of communications support or assistive devices. This particularly affected women, who are more likely to bear the caring responsibilities[213], or to be the sole carer of one or several children or relatives with disabilities[214].

Some countries made exceptions to allow for the continuation or alternate provision of services. **Latvia**, for example, continued assistance services[215]. Some online provision, or disability-related facilities, could remain open. Services supporting confinement are discussed below in the social protection section.

In terms of confinement, persons with disabilities faced a mixture of some stricter confinement measures and then, through the pandemic, some exceptions to limit the disproportionate effects that they were facing. Some persons with disabilities were instructed to follow the stricter confinement measures that were imposed on older persons. Persons with disabilities in residential settings, whether community-based or in institutions, often faced quite severe confinement. Exceptions were developed, such as those in **France**, that allowed longer outings[216] or **Spain**, which allowed outings with assistants[217]. After complaints in **France**, blind persons and persons with low vision were exempted from carrying the self-certification that designated purpose of an outing[218]. Supermarkets in many countries offered priority shopping hours for older persons and often persons with disabilities too. In several countries that offered disability-related

exceptions, a permit or certificate was needed to provide proof of disability.

In some countries, there was not such a strict nationwide lockdown. **Sweden** is famous for this approach, **Iceland** did not lockdown either, and **Germany** had decisions taken at the regional level, and initially relied on extensive testing and tracing. By the end of 2020, however, Germany is going into a strict lockdown.

Discussion with EDF Members in these countries highlights the mixed results for persons with disabilities when it comes to decentralised responses. This led to continuity of education in some countries, which was a positive experience as it caused less disruption to the daily lives of families. Decentralised decision-making often included the suspension of many services in inconsistent and unpredictable ways. For example, one of the services that was suspended once lockdown was imposed in **France** and **Belgium**, was assistance to rail passengers with disabilities[219]. This was a violation of EU law[220] and further limited the equal right to travel for persons with disabilities, who already encountered numerous accessibility and assistance-related barriers. A decentralised approach also created a burden on individuals and their households who want or need to take more cautious approaches

Serious concerns are being raised by the disability community about the dangers for persons with disabilities in the near future as lockdowns are lifted. In May, the Commissioner for the Rights of Persons with Disability in **Malta** raised the concern that "we risk ruining 30 years of work in accessibility" because the disability sector "remained an afterthought" in the policies for reopening[221]. In the **Netherlands**, the EDF's national member, Ieder(in), said that persons with disabilities had been "forgotten" during the lifting of measures[222].

The issue of masks, or face-coverings, also developed through the pandemic. In many countries – including, among others, **Czech Republic**[223], **Lithuania**[224], **Germany**[225], **Poland**[226], **Switzerland**[227], and the **United Kingdom**[228] – exemptions to mandatory face covering are made for persons with disabilities and/or the persons with them. In some cases, this policy has not been clear to the general public and is

not necessarily communicated in the announcements of rules on face-covering. Persons with disabilities not wearing masks have reported harassment[229].

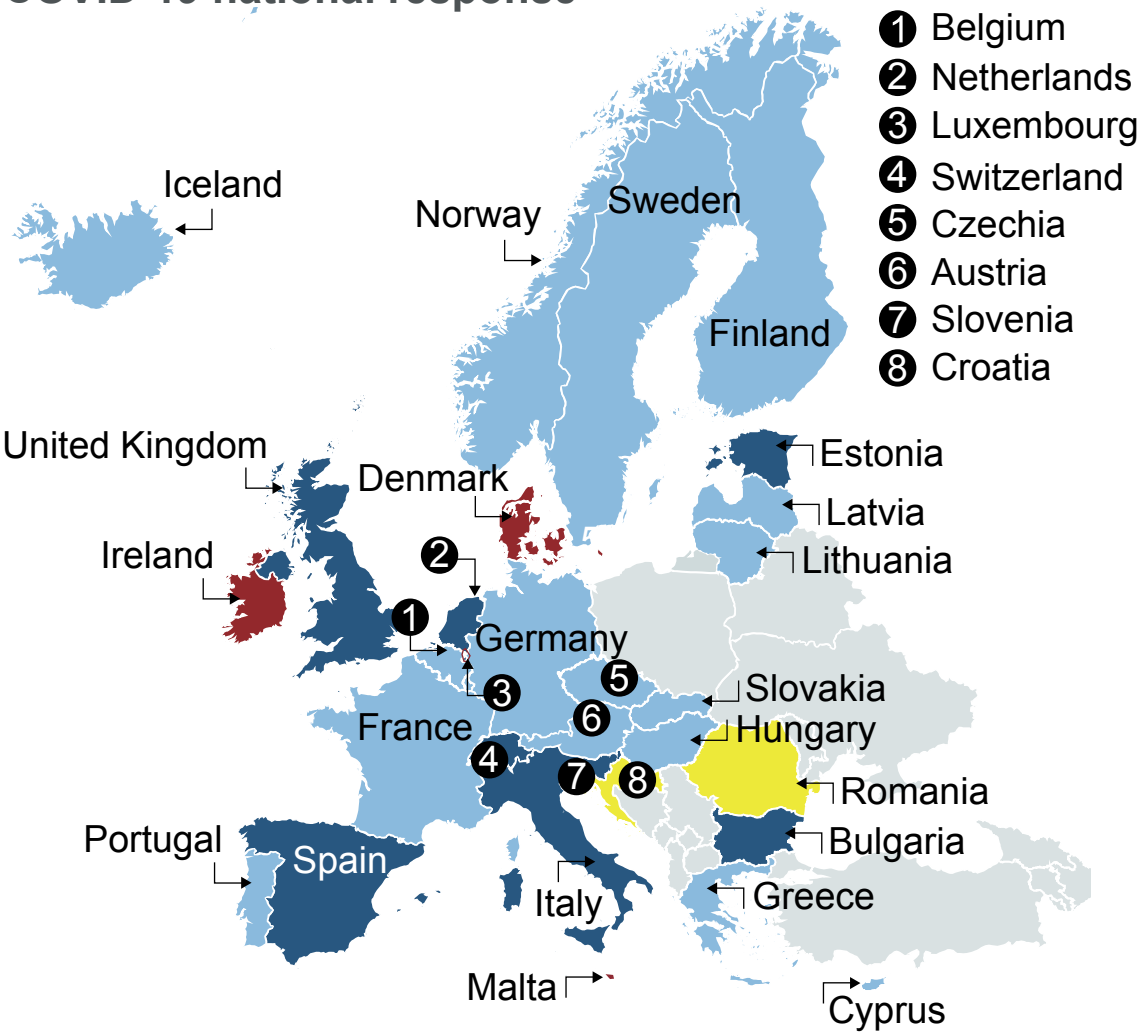
Many persons with disabilities are very disadvantaged with traditional face masks – for example people who rely on lip reading for communication. In these cases, members of EDF campaigned for the use of transparent face masks which enable people to lip read (even if this is not as easy as without a face mask). Promotion of transparent face masks has been prominent in France, with the adoption of the inclusive mask[230].

Involvement of persons with disabilities

It is one of the obligations of the CRPD that State Parties "closely consult and actively" involve persons with disabilities, through their representative organisations, in decision-making processes concerning issues that relate to persons with disabilities. In countries across Europe, this obligation was not fulfilled during the COVID-19 crisis, which, as is shown in its effects, had a disproportionate impact on persons with disabilities.

Existing limitations in the involvement of persons with disabilities in decision-making and creation of public policy means that structures are often not in place to facilitate this. In cases where governments did consult persons with disabilities through the pandemic, it was often done in an ad hoc manner or limited to specific issues.

Level of involvement of persons with disabilities and their representative organisations in COVID-19 national response



- Participation: in national level COVID-19 taskforce or equivalent
- Consultation: official consultations with DPOs to determine response
- Advocacy: DPO-led, or more ad hoc communication with government
- Other/unknown

That said, there were several countries where persons with disabilities were involved through formal structures. One of the most notable is **Denmark**, where a partnership was formed at the end of April with civil society organisations, including DPOs. The government also provided €3 million funding to the Danish Organisation of Persons with Disabilities for initiatives fighting loneliness and mental health consequences of the lockdown[231]. In **Ireland**, the Disability Federation of Ireland was a part of the National Public Health Emergency Team Vulnerable People Subgroup and collaborated with different parts of government. However, in summer 2020 the Vulnerable People sub-group was disbanded. There has not been involvement from people with disabilities or their representative organisations in groups set up since such as our vaccine taskforce and other bodies[232]. In **Belgium**, the Regional Disability Advisory Councils were, to some extent, involved in Regional Task Forces[233].

There were many cases where persons with disabilities were consulted on specific issues or at specific points in the crisis. This ranged from quite high-level meetings, such as the Prime Minster of **Italy** meeting with the Italian Federation of DPOs, to some technical involvement or other participation in consultation meetings and advocacy through various public and informal methods used by DPOs[234]. In **Slovenia**, DPOs were consulted in the development of anti-corona legislation and some of their suggestions were adopted[235]. In **Spain**, there was a range of technical involvement, including Fundación ONCE being part of the development of accessibility in new technology and applications[236]; CERMI's dialogue with the Government and Parliament advocating for persons with disabilities; and the National Disability Council being in the Board that oversaw a seroprevalence study which, as a result of their influence, disaggregated data by disability[237].

In many cases the advocacy of DPOs provided important changes to policies managing the crisis. One of the most frequent examples is the provision of sign-language, and other measures for accessible communications, which were often adopted after successful advocacy by the disability movement.

The advocacy and awareness of DPOs and the disability sector on the issues relating to persons with disabilities often is in sharp contrast to the extent of the efforts made by the governments to

consult them. In **Austria**, an open statement criticised crisis task forces for not including persons with disabilities.[238] In **Ireland**, the Irish Human Rights and Equality Commission expressed concerns about the lack of participation of persons with disabilities and DPOs in the development of the COVID-19 Response[239]. In **Sweden**, DPOs requested to be on a committee discussing the aftermath of COVID-19 and were denied[240]. A notable example is **Malta**, where the Commissioner for the Rights of Persons with Disabilities formed a Disability Task Force whose advice was taken in some specific areas but was not necessarily involved more systematically[241].

The lack of government capacity on basic disability issues, was prominent throughout the crisis. This also revealed a range of different roles that DPOs play, which are described in the next chapter. As well as representation and advocacy, DPOs were often involved in service delivery directly or through partnersgip with government, and in gathering data and information on persons with disabilities. Many of these roles are the direct responsibility of government and government agencies and DPOs are filling the gap of lack of capacity on this issue. The mandate of civil society organisations in the future will be coming into question, as will their funding as the funding for these organisations everywhere is restructured, or cut, in response to the economic downturn. In **Estonia**, in fact, DPOs face a considerable decrease in funding already as their income source – based on a tax on gambling – has been reduced[242].

Health care

The right of healthcare of persons with disabilities was highly affected during the pandemic due to inaccessibility, discrimination and suspension of regular healthcare services.

For COVID-19 health care, discrimination did occur at any point in the chain of care, from seeking and accessing testing or treatment, to admission to hospital, to priority or access to treatment in hospital. Several countries have seen discrimination reported in lack of referral of certain patients – including persons with disabilities and older persons – to hospitals for medical treatment.

- In **Belgium**, it is reported that ill persons were not referred to hospitals from long-term care facilities[243].

In **Sweden**, some hospitals informed "at-risk" groups that they would not be admitted to hospitals[244].

In the **United Kingdom**, some local health practices requested patients to sign "do not resuscitate" orders. Many of these were retracted afterwards[245].

Health-seeking behaviour will have changed for all persons during the pandemic. In many cases, health systems encouraged people with COVID-19 symptoms to stay at home until the symptoms progressed further. As the above examples show, many groups of people may have been disincentivised further from seeking treatment.

Questions of prioritisation within healthcare systems became a subject of public debate, which often included speculation on the supposed need to deprioritise treatment for COVID-19 for certain groups. This speculation that healthcare should be withdrawn from older persons, or persons with health conditions or "vulnerability" is a generalisation that reproduces harmful stereotypes and often carries an implication that some peoples' lives are more valuable than others. Among other effects, these discussions contributed to a sense among many persons with disabilities of being left behind and without the support of medical or other systems in a situation of emergency.

The widespread concerns within the disability community were not without substance. Often based on what was being recommended or practiced within health systems, many countries had to take action to prohibit discrimination based on disability in priority for access to health care.

- In **Finland**, the Ministry of Health issued guidelines in response to concerns that some social and healthcare authorities were going to limit access of persons with disabilities to health care[246].
- In **Luxembourg**, the National Ethics Commission issued a position paper at the end of March[247].
- In **Ireland**, the Department of Health's "Ethical Framework for Decision Making in a pandemic" included disability in its third version, after concerns were raised by representatives of persons with disabilities[248].
- In **Italy,** the Italian Commission on Bioethics released an expert

opinion prohibiting discrimination after guidelines from a medical society had implied discrimination[249].

- In **Spain**, the Ministry of Health made a report prohibiting discrimination on the basis of disability to prioritise patients or determine access to healthcare resources[250]. This came after a Society for Intensive Care Doctors had given guidance on triage that included persons with cognitive disabilities in exclusion criteria to access intensive care units[251].
- In the **United Kingdom**, a joint statement from medical and care bodies made clear that blanket policies should not be taken after a range of "do not resuscitate" guidelines being introduced. In health care in England, clinical guidelines on priority were adjusted after an initial version would have led to discrimination against people with learning disabilities, among others[252].

Further assessment is needed in each of these countries – and other European countries – to see the extent of discrimination before these guidelines and whether the issuing of new policy did indeed remedy the situations they set out to. It is also needed in countries that did not set overall policies on health prioritisation. In **Germany,** concerns were raised that the absence of a triage policy was leaving decisions to associations of medical professionals[253].

The COVID-19 response also had an impact on access to general preventative and curative healthcare. In many countries healthcare provision beyond COVID-19 treatment was suspended or deprioritised. Some countries made decisions on "essential" healthcare, and often services were discontinued because of lockdown restrictions. This affected therapy, home care, mental health support, and many other treatments that persons with disabilities depend on. In **Denmark**, a survey of 892 persons with disabilities and family members showed 67% reporting that lack of access to rehabilitation and other services had worsened their health[254].

Long-term care facilities and institutions

As noted above, 30-60% of COVID-19 deaths in European countries took place in long-term care facilities. It is estimated that over a million children and adults with disabilities live in institutions across the EU (then including the UK) and **Turkey**[255]. This subject needs

urgent and sustained attention as the COVID-19 crisis revealed the often very questionable conditions of these facilities. This must renew and redouble our commitment to deinstitutionalisation and provision of adequate funding for independent living and community-based services.

Concerns on lack of data were raised in many countries and include those raised in **Portugal** about the lack of information on persons with disabilities in institutions[256]. In many countries, guidance was limited and late, and **Italy** was not alone in issuing guidance to care facilities after lockdown had come into place[257].

Many countries failed to ensure that sufficient precautions were taken to protect staff and residents, including personal protective equipment, timely access to testing and treatment, access to information and means for accessible communication for residents, and adequate human resources.

In many countries, these facilities had not been properly considered in the nationwide pandemic preparedness plans.

In many cases, the response, when it came, was one of extreme protection of "at risk" age groups. In some countries, this also applied to institutions of persons with disabilities (regardless of whether they were in those age groups), as well as to some supposedly community-based services. A measure taken in many places was a ban on external visits or free movement. This had devastating effects of loneliness and isolation for residents and, as the Ombudsman in **Slovakia** noted, "the rights of people with disabilities to maintain contact with people outside are disproportionately restricted"[258]. In many cases, persons with disabilities, including children, were left isolated for months with no outside contacts.

Some countries found ways to maintain visitation and movement rights for people in long-term care facilities. In Belgium, visitations to persons with disabilities in institutions were stopped but with exceptions for end-of-life visits and other circumstances[259], in Finland, the handbook for disability services on COVID-19 instructs that prohibitions be proportionate and not limiting the right of persons with disabilities to visit their family homes[260]. **Austria**[261], **Germany**[262], **Luxembourg**[263], and **Switzerland**[264] took measures to allow the continuation of visitations with special measures.

As well as limitation on visitation, there was often a curtailment of services available to people living in long-term care facilities or institutions. These could have been health or rehabilitation services, care plans, or social services. In terms of health care there were often more problematic issues. As mentioned above, there was some discrimination and/or lack of access to testing or treatment for COVID-19 for people in long-term care facilities or institutions, and, in some cases, people were not admitted into hospitals. Furthermore, in the **United Kingdom**, as the health system prepared for COVID-19, persons were discharged into care homes without testing for their COVID-19 status and this caused the spreading of the disease in a deadly way[265].

The situation in long-term care facilities and institutions, as well as the crisis-related changes to community-based living facilities or group homes, continues to be of grave concern.

Social Protection

Governments took unprecedented actions during the pandemic to keep economies working and to boost social protection. Many governments offered some specific welfare for persons with disabilities and adjusted disability-related benefits so they could continue through the pandemic. However, these were often relatively small amounts of support.

Some structures for social protection were adapted during the pandemic in an attempt to mitigate the impact on persons with disabilities and their families. In **Belgium**[266], **Latvia**, **Slovenia**[267], **Sweden**[268] and **Iceland**[269] there were increases to disability allowance or one-off payments to help cover extra costs incurred by the pandemic. In **Spain** a Minimum Living Allowance was put in place to support people experiencing economic vulnerability[270]. In **Bulgaria**[271] social service tax payments were suspended during the time these services were suspended. In **Bulgaria**[272], **Malta**, **Norway**[273] and **Luxembourg**[274] paid leave was granted to employees with disabilities or who have a family member with a disability, and in **Estonia**[275], **Lithuania**[276], **Poland**[277], **Portugal**[278], **Switzerland**[279] and **Germany**[280] a form of financial compensation was given to families. In **Czechia**[281] and **Germany**[282] a special care allowance was granted to families of persons with disabilities who would normally have attended care centres closed because of the virus.

The COVID-19 crisis has demonstrated how precarious social protection for persons with disabilities can be. As the section on lockdown and confinement shows, services for persons with disabilities were all too vulnerable to suspension and with no provision of alternatives. Benefits and services can easily be changed, and those allocated are hardly sufficient to address the circumstances caused by ill-health and the economic and isolation challenges that persons with disabilities and their support network face during this pandemic.

While gaps in government response are in evidence throughout Europe, individuals, families, communities, and civil society have filled those gaps. A remarkable effort has been made to support persons with disabilities through this crisis. Public attitudes towards disability continue to change and the lives and circumstances of persons with

disabilities in many countries are increasingly featured in mainstream media.

A range of social protection measures were used that targeted persons with disabilities and their families throughout the pandemic. Many countries gave support to families or caregivers of persons with disabilities and some countries developed initiatives for persons with disabilities in the workplace. There were a range of services related to lockdown including supporting those in confinement or adjusting delivery of disability-related benefits. However, some cases were noted of cuts being made to disability payments even during the pandemic. In **Cyprus** some persons with disabilities saw the termination of their Minimum Guaranteed Income payments[283]. In Portugal, many persons with disabilities saw their regular treatments and therapies cancelled[284].

Many countries gave support to those responsible for the care of persons with disabilities, and this was often targeted at families of children with disabilities. **Czechia** gave a care allowance[285], **Iceland** gave a fixed benefit[286], and **Slovakia** provided a compensation[287]. **Austria**[288], **Luxembourg**,[289] **Norway**[290], and **Portugal**[291] provided types of paid leave. **Estonia** gave parents of children with disabilities some financial support[292], **Germany** gave compensation for loss of income[293], **Lithuania** allowed a sickness benefit for those assisting persons with disabilities[294], and **Malta** gave a Parents Benefit Scheme[295].

For persons with disabilities in training and work there were initiatives for both the person with disability and the employer. Persons with disabilities in Malta who, on medical advice, could not go to work due to COVID-19, and could not work from home, received weekly direct payments and had other social protection safeguarded[296]. In **Poland**, the Government increased its share of monthly co-financing for the salary of employees with disabilities and compensation for those employed in Vocational Activity Establishments[297]. In **Germany**, €70 million was made available for integration offices to support those in sheltered workshops who lost income[298]. Decisions about who can or should work from home are complex and their complexity increased as countries came out of lockdown. In the **United Kingdom**, for example, the Trade Union Congress raised concerns about a "heartless and reckless" return to work[299].

Examples of measures to support and maintain services for persons with disabilities during lockdowns

- Cash payment to persons with disabilities or their family
- Funding for support to persons with disabilities

During lockdown and confinement there was a range of measures taken to provide support and to maintain continuity of services. Many countries, including **Belgium**[300], **Iceland**[301], and **Slovenia**[302], gave cash payments to persons with disabilities and **Latvia** gave a benefit to families with children with disabilities[303]. However, these were mostly one-time payments between €100 and €300. In **Belgium**, €50 is added per month to those receiving disability benefit. In **Spain**, a fund was created to support persons with disabilities, older persons, and homeless persons with alternative services including home assistance[304]. In **Bulgaria**, €22.5 million funding was given to municipalities to help them reach target groups – including persons with disabilities – with food, medicine and other essentials[305]. **Hungary** took measures to survey persons with disabilities to be able to respond to their needs[306].

As well as these supports of cash, services, or provision in-kind, many countries adopted measures to allow social protection systems to function in a way that is compatible with confinement or physical distancing. Many countries automatically renewed disability certificates or eligibility to benefits. This was the case in **France**[307], **Greece**[308], **Latvia**[309], **Lithuania**[310], **Slovakia**, **Slovenia**[311] and the **UK**[312].

Impact across societies and economies

All areas of life have been impacted by the COVID-19 crisis. Alongside the public health crisis and ongoing confinement, there has been the creation of a “1.5 metres society”, as Ieder(in) has called it in the **Netherlands**[313], an economic crash, and an unprecedented role of government in daily life. In the assessment of national responses, many issues relating to the “1.5 metres society” and the adaptations that persons with disabilities need for it have been discussed. This report highlights some of the dynamics in employment, work, and education.

Education

During COVID-19 a researcher based at EDF studied the impact of the crisis on education and the results are available here[314].The closure of schools in the majority of European countries particularly affected children with disabilities and their families. The length of closure has also varied widely. Some countries, following WHO Office for Europe's advice, reopened schools and kept them open in autumn as the second wave hit after the summer. During the second wave many countries gave priority to the continuation of education, such as **Ireland**, and **Belgium**. In some countries, as the year ends schools have closed, such as in **Romania**, for example.

Nearly all countries had challenges with making distance learning fully accessible and inclusive. There were many factors contributing to this: from the family's ability to access technology, to inaccessible e-learning platforms, and the lack of one-on-one support. Some countries took a proactive policy response, including **Greece**, which issued a directive on distance learning for pupils with disabilities in mid-March[315], and **Italy**, where the Ministry of Education requested school directors to carefully consider the needs of students with disabilities[316].

Countries' responses to ensure continuity of inclusive education are a mixture of inclusive social measures and actions to make distance learning more inclusive. Among the social measures, some countries could offer support to bridge the technological and digital divide, including **Lithuania**, which bought digital devices for students from lower socio-economic backgrounds[317], and **Malta** who distributed laptops and tablets[318]. Other support included allowances for parents (for example **Estonia**)[319], priority for reopening of special schools, sign-interpreters, and other systems to support parents and caregivers. **Iceland** kept schools open for students seen as vulnerable[320]. Making distance learning more inclusive included ensuring that e-platforms were accessible and that there was availability of one-on-one support and/or helplines for students and their families.

Many challenges in education during the public health emergency continue. While many countries have reopened education, education service disruptions persist. Those pursuing online or "hybrid" learning

will need to take substantial actions to ensure inclusive learning opportunities through accessible platforms and measures to support students studying from home.

Children with disabilities, according to the CRPD, have the right to quality inclusive education. This crisis has again highlighted the gaps children with disabilities still face

Employment

Persons with disabilities came into the crisis facing exclusion in all areas of the world of work[321]. In Europe persons with disabilities were already less likely to be employed than persons without disabilities. 50% of persons with disabilities were in employment compared to 75% of persons without disabilities[322]. Some of these barriers to employment remain persistent and structural[323]. Even without the specific issues of COVID-19, they will all be exacerbated by an economic downturn, where persons with disabilities are often more likely to be made redundant and will find it harder to get back into work.

As the Irish Human Rights and Equality Commission noted in **Ireland**:

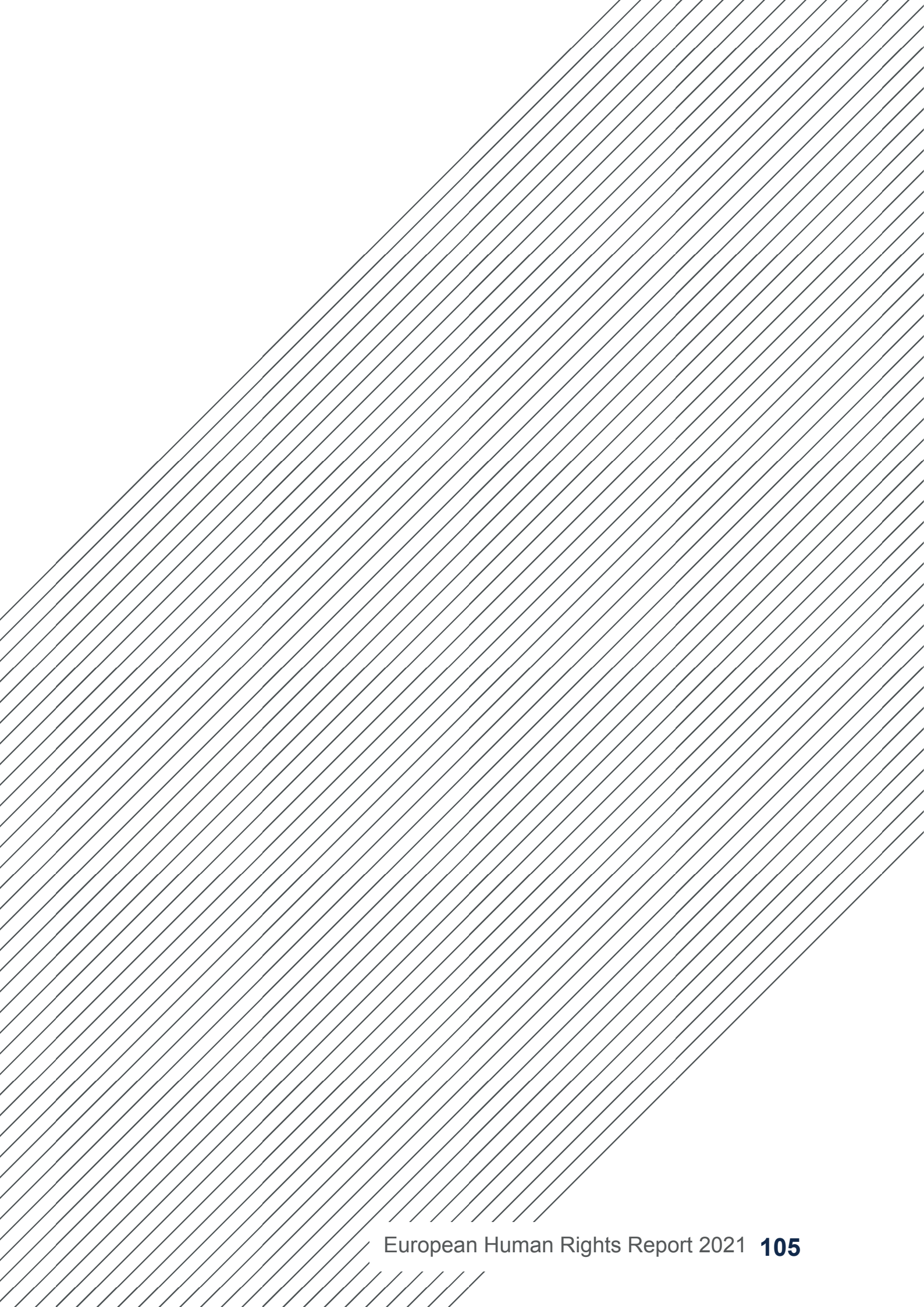
There is a real risk such discrimination [on the grounds of disability] may become even more widespread in the coming period of economic turbulence. In combination with rising additional costs of living with a disability due to expenditure on PPE [Personal Protective Equipment], any such further exclusion from the labour market places persons with disabilities at increased risk of poverty and social exclusion[324].

As noted above, there were some social protection measures introduced to support persons with disabilities who had to stop working because of COVID-19. As well as these measures often being limited, there were also a number of complications for persons with disabilities in continuing work. For those working from home, there is the need for accessible technology and the adaptations they may have already received in the workplace. For those whose work is on site, there are different factors that made persons with disabilities more at risk from COVID-19 transmission. Somepersons with disabilities had an increased health risk from COVID-19. Others faced increased risk because transport or assistance put them more in close contact with people that is recommended.

The COVID-19 crisis will have an impact on the environment that enables persons with disabilities to seek employment, such as in transport and assistance services, access to training opportunities and development of professional skills, as well as the effects on the pipeline of talent caused by interruptions in education.

There are, however, for some positives effects for persons with disabilities that have come out of the COVID-19 crisis. Work-from-home had been requested by many employees with disabilities long before this year and has now become routine in many occupations. While there was a concern that employers cut back on staff, there has been, in some areas, a renewed attention of employers to disability issues and the willingness to provide the best adaptations for their employees[325].

In **France**, during the first wave of the pandemic, the government safeguarded the payment of salaries to 120 000 employees with disabilities, to protect them against losses caused by the inability to continue working. A total of 160 million euros was spent during the first eight months of the pandemic. There has also been increased flexibility for workers to move to part-time employment or take paid sick leave if they are vulnerable to severe COVID-19 symptoms. A €4000 bonus was also guaranteed to any business or association of any size hiring a person with disabilities for more than three months from the time of the pandemic up until the 30th of June 2021. A bonus of between €5000 and €8000 was given for companies or organisations signing an apprenticeship contract with a person with disabilities between the 1st of July 2020 and the 28th of February 2021. Measures have also been taken to promote the career development and facilitate recognition of qualifications for persons with disabilities working in the French public sector, such as treating work experience in the form of apprenticeships as a proof of expertise in the same way as formal education diplomas[326].



Chapter 7: Response of the disability movement

From the onset of the COVID-19 pandemic, the disability movement, played an active role in dealing with the crisis, which this chapter will summarise. In order to include the variety of initiatives from the disability community, we include actions from representative organisations of persons with disabilities (DPOs), disability activists and allies, including service providers, equality bodies, and national human rights institutions.

The CRPD calls on all States Parties to ensure meaningful participation of persons with disabilities through their representative organisations, in all matters that concern them (article 4.3 CRPD). Organisations of Persons with Disabilities exist and mobilise themselves to fulfill this role. The role of DPOs during this pandemic has gone far beyond traditional boundaries. EDF's members reported a very increased demand from members for support, information, guidance, training and exchange, and joint advocacy at both national and EU levels.

This chapter serves as a record of the contribution the disability movement has made, mainly focusing on Europe. It is a reminder of the importance of the slogan of the disability movement 'nothing about us, without us'. Each stage of the pandemic has brought new challenges, and at each stage DPOs looked for solutions, often with very limited means.

Understanding the impact of COVID-19 on persons with disabilities

The source of most initiatives to alleviate the impact of the pandemic on persons with disabilities in Europe has come from the disability movement. DPOs have been assessing the impact, hearing from their members, and working to ensure their concerns have been met from the onset of the pandemic. This knowledge of the impact on persons with disabilities in general, and people from specific impairment groups, underpins all our actions on COVID-19.

The pandemic, caused by a novel virus, has had unexpected and wide-reaching consequences. The measures taken to alleviate it have had unique impacts. These unique ways in which the pandemic has impacted on the lives of persons with disabilities have been documented and communicated to policy makers by the disability movement. They have created a wide range of resources that have contributed to accessible information, advocacy, policy development, and service provision. Unfortunately, not all the knowledge on the impact of COVID-19 shared by the disability movement has resulted in disability inclusive responses from policy makers.

DPOs have identified a range of issues, such as:

- The negative consequences of rules for public behaviour that do not take into account persons with disabilities. Examples of areas where exceptions should be made:
  - » Physical distancing when you use personal assistance or a guide;
  - » The obligation to shop alone, when you may usually use an assistant to do this independently;
  - » The obligation to wear face masks for people with disabilities who due to their impairment cannot tolerate this. The face mask also impacts communication for Deaf or hard of hearing people, for anyone relying on lipreading, and often makes it harder for partially sighted people to recognise others. Face masks are difficult for some to wear/ manipulate[327].
- Lockdown measures created fear, anxiety, and insecurity for many persons with disabilities due to the limitation of their freedom of movement and destruction of routines.
- The predicament of children and students with disabilities who have lost all support when learning moved online.
- The increase in segregation and isolation of people with disabilities in institutions and closed settings, no longer in touch with the outside world, including family members, support network, and allies and at higher risks of infection and death[328].
- The lack of specific disability-related support services.

- The lack of access to COVID-19 testing, treatment, and provision of reasonable accommodations when hospitalised. For some persons with disabilities COVID-19 testing methods are invasive and cause stress and anxiety[329].
- Lack of accessible information and communication on COVID-19 testing and treatment.
- The economic upheaval the pandemic will have on people most exposed to poverty. Persons with disabilities lost their jobs, or did not receive reasonable accommodations, support, or accessibility technology necessary to continue working at home, or new online work platforms were inaccessible to them.
- Public transport became unavailable and no longer accessible to some persons with disabilities due to the changes made in frequency or reduction in assistance provided to passengers with reduced mobility.
- The risks faced by women and girls with disabilities to domestic violence and abuse, which has dramatically increased during the pandemic.

Advocacy and self-representation to decision makers

In early March 2020 in Europe, it became clear to the public that COVID-19 was a force which was rapidly changing our daily lives, and threatening our survival. The impact on persons with disabilities, and their exclusion from the COVID-19 response was immediately visible, as public health announcements were inaccessible at the EU level and in member states. The disability movement started to advocate before decision makers at all levels from that point on and continue to this day.

At the national level

EDF members in the first most hard hit countries immediately started to defend their members from the impact of the discriminatory lockdown measures. In **Spain**[330], **France**[331], and **Italy**[332] – countries which had lockdowns from March – EDF members advocated for exceptions to the lockdown measures, such as the prohibition to leave one's home or to only be accompanied by someone from your family. In **Czechia**, **Poland,** and **Bulgaria** – where an obligation to

wear face masks was imposed for all public places – DPOs advocated successfully for exceptions to be made for persons with autism.

Other examples of positive results of advocacy from national DPOs:

- In **Greece** and **Lithuania**, our members obtained a special leave from work for all parents of persons with disabilities for as long as the measures of the lockdown were in force.
- In **France**, the government launched a specific helpline for supporting autistic adults that are isolated.
- In **Portugal** and **Spain**, COVID-19 health hotlines became available in national sign languages through video-relay services. In Ireland, the Health Service Executive approved guidelines to enable communication between Deaf persons and health care professionals through remote interpreting or directly in Irish Sign Language.
- In **Germany** and **France**, governments started providing information on COVID-19 in Easy to Read.
- In the **UK**, the National Institute for Health and Care Excellence changed its intensive care unit triage protocols[333] to ensure that autistic people are not subjected to discriminatory assessments preventing them from accessing lifesaving treatments.

At the EU level

EDF sent letters[334] to the leaders of institutions, based on the input of our members at the national level, asking for a disability-inclusive COVID-19 response.

EDF published a statement with its members about persons with disabilities living in institutions[335] where they are exposed to increased risks of infection, physical and psychological abuse due to isolation, neglect, and even abandonment. Another statement stressed the very difficult situation of persons with disabilities stripped of community based support services and other protective equipment[336] during COVID-19. We also issued recommendations on exit measures for transport services in light of COVID-19 to ensure that full diversity of passengers were considered when countries initiated partial lifting of confinement measures after the first lockdown in Spring 2020[337].

The **European Union of the Deaf** (EUD) highlighted, repeatedly, the lack of accessible announcements by the European Commission and national Deaf associations advocated at the national level. The organisation requested the televised or streamed (whether live or pre-recorded) announcements related to the coronavirus outbreak to be interpreted in real time into International Sign, with sign language interpreters being on screen and clearly visible the entire time of the broadcast, as the EU is under a legal obligation to make its communications, announcements, and information accessible to all[338]. As a result of this advocacy, there were some measures taken to make announcements accessible, but this is still not a routine practice as we report in chapter 5. The Commissioner for Equality, Helena Dalli, reacted to EUD's and EDF's requests and confirmed that the communications from the President of the European Commission were to be made available in International Sign.

Inclusion Europe submitted a petition[339] on the neglect and discrimination faced by persons with intellectual disabilities and their families during the pandemic to the Petitions Committee in the European Parliament. A debate was organised and a resolution was adopted on 1st July 2020.

At the international level

EDF is a member of the International Disability Alliance (IDA), which brings together DPOs at the global level. As part of the international movement, EDF worked with IDA to advocate at the UN level for UN agencies to make their responses inclusive and accessible. The UN adopted its Disability Inclusion Strategy[340] in 2019, and has a secretariat in the UN Secretary General's office responsible for coordinating the work on the Strategy. The UN Secretary General and other UN agencies, in consultation with the disability movement, released a series of CRPD compliant guidance and commitments to ensure the CRPD was part of the UN response. IDA wrote letters to UN agencies and campaigned publicly on non-discrimination in access to health care. Responding to the advocacy of IDA and its letter to the World Health Organisation, the Secretary General announced his commitment to ensuring equality and access for persons with disabilities via social media. This commitment for equality at the highest level of the UN is in stark contrast with the lack of disability inclusive response at the EU level.

Technical support to government

Some countries reached out to organisations of persons with disabilities and involved them in their taskforces or bodies created to respond to the pandemic.

- EDF Board member from **Italy**, Giampiero Griffo, was appointed to the Italian government's taskforce on COVID-19 pandemic[341], as an expert and coordinator of the Technical-Scientific Committee of the Observatory on the Condition of Persons with Disabilities.
- The **Icelandic** Association of the Deaf is working closely with its government's Directorate of Labour to ensure that Deaf people do not lose their jobs, as they are at risk of unemployment during the COVID-19 pandemic.
- In **France**, the Collectif Handicaps[342] provides technical support to the government in the development of its COVID-19 responses. An online resource page of the Minister[343] responsible for the rights of persons with disabilities is regurarly updated with information from the French disability movement.
- In **Denmark**, EDF member Disabled People's Organisation Denmark[344] (DPOD) was consulted early on by their government in relation to ensuring persons with disabilties were included in the pandemic response. They suggested a national phone number run by authorities to provide information to those who needed it, information in Easy to Read, and close cooperation between authorities, civil society, and trade unions. DPOD has also received funding from their national government to combat isolation of persons with disabilities, promote online cooperation, etc.
- In **Ireland**, EDF member Disabled Federation Ireland[345] (DFI) has been included in the national taskforce[346] designing responses to the crisis.
- Mental Health Europe's member in **Spain** produced guidelines[347] for public bodies and security forces on how to address persons with psychosocial disabilities during the pandemic

Human rights monitoring and reporting

The disability movement has been closely monitoring and reporting human rights abuses during the pandemic. Where specific violations were discovered, for example the appalling neglect of persons with disabilities in institutions, disability organisations collectively documented and advocated for redress.

- In **Spain**, the national umbrella organisation submitted a comprehensive reportthe UN Committee on the Rights of Persons with Disabilities.
- The **Italian** organisation of persons with disabilities submitted a report[348] to the United Nations Committee Against Torture.
- In **Finland**, Validity Foundation, Law Firm Kumpuvuori Ltd. and the European Network on Independent Living have filed a collective complaint[349] to the European Committee of Social Rights arguing that the COVID-19 emergency measures violate the rights to health, to social services, and to independence and inclusion in the community of persons with disabilities in Finland. The organisations called on the Finnish Government to release persons with disabilities living in institutions and urgently provide them with support services in the community.
- In **Germany**, the German Disability Forum (Deutscher Behindertenrat DBR), which represents more than 100 DPOs published an analysis of the COVID-19 crisis and a Catalogue of Demands stating that daily life of many persons with disabilities had been far more negatively affected by COVID than the rest of the population[350]. DBR claimed to build up emergency pools for personal assistance and care in all local communities and to grant financial support for the families concerned
- The disability movement joined forces at different levels and published the **COVID-19 Disability Rights Monitor Report**[351] in October 2020. The report is the result of a major global initiative aimed at conducting rapid, independent monitoring of state measures to assess the impact of COVID-19 on persons with disabilities.
- In addition to the report, the COVID-19 Disability Rights Monitor sent an urgent appeal[352] to the **Romanian** Government to ensure

equal access to COVID-19 medical treatment for residents of an institution, followed up by a communication from the UN Special Rapporteur on the Rights of Persons with Disabilities. Separate statements were also published on the situation of persons with disabilities in institutions, on police violence and abuse, and on access to food, medication and essential supplies.

- DPOs had positive engagement with national CRPD monitoring mechanisms, as, for example, in **Spain** and **Belgium**, during the pandemic
- Due to EDFs advocacy, the European Fundamental Rights Agency's regular reporting[353] on the implications of COVID-19 on fundamental rights in the EU contains specific information on the rights of persons with disabilities.

Direct support and services to their members and to the public

Since the onset of the pandemic, DPOs have been supporting their members in a range of ways.

They have informed their members about COVID-19. For some persons with disabilities, information was not available to them in accessible and understandable formats and DPOs provided this. DPOs representing specific impairment groups carefully assessed the implications of the pandemic on their members and provided this information on their websites, to then be used by their members, but also by the government, service providers, and others. DPOs also provided direct support to their members in education, health care or in other daily activities.

Some examples are listed here below. More examples can be found on EDFs dedicated webpage[354].

- **Inclusion Europe** provided extensive accurate and up to date information on COVID-19 in Easy to Read in different languages[355].
- **Autism Europe** created an online resource page[356] with accessible tools and information on COVID-19 and published a report on the impact of COVID-19 on autistic people[357].

- The **European Union of the Deaf** made information available in international sign on the outbreak and containment measures, as well as COVID-19 income support schemes, and compiled resources[358] in national sign languages.
- The **European Network of Independent Living** collected personal experiences of persons with disabilities during the pandemic and compiled information about the activities of its members[359].
- **EURO CIU** which represents cochlear implant users created guides[360] for their members.
- The **European Blind Union** created a COVID-19 resource page[361].
- **Mental Health Europe created** a map[362] of helplines and services to support mental health during the COVID-19 crisis.
- The **Spanish Committee of Representatives of Persons with Disabilities** (CERMI) published an emergency operational document[363] advocating for adequate health care without discrimination on the grounds of disability during the COVID-19 crisis.
- **CERMI Women's Foundation** published a guide for women and girls with disabilities on protection against violence and abuse during these times of COVID-19. It also launched weekly webinars[364] "No estás sola" [You are not alone], creating a platform of exchange and circles of mutual support groups for women with disabilities and mothers of children with disabilities to discuss their challenges.
- In **Italy**, the organisation Fondazione Oltre Il Labirinto Onlus created an online support helpdesk[365] for Italian families with autistic people.
- In the **UK**, DPOs and allies compiled a range of resources for those using direct payments and personal assistance.
- In **Northern Ireland**, Disability Action published a report[366] on the impact of COVID-19 on disabled people, as part of efforts to ensure a disability-inclusive response.

- Many national associations of the Deaf in Europe worked with public authorities and audio-visual broadcasters to ensure that public information and TV educational programs are accessible in national sign languages[367]. For example in **Lithuania**, the speeches of the President and all press conferences on COVID-19 were interpreted in the national sign language for the first time. Also in **Belgium**, Deaf interpreters were used on a daily basis by public authorities to provide interpretation.
- **National Associations of the Deaf** provided distance education in national sign languages for Deaf children; ensured accessible communication in healthcare, either through in-person interpreting or through video remote interpreting; provided information for Deaf women victims of domestic violence; provided devices and upskilling programmes to fight isolation, especially of Deaf elderly; and operated hotlines on COVID-19, mental health and domestic violence in national sign languages[368].
- Organisations representing blind and partially sighted people offered services to their individual members, helping them with daily life activities such as shopping or administrative tasks[369].

Service providers

EDF has a wide membership, which includes a range of disability services providers who work closely with us to promote the rights of persons with disabilities. Our members in the field of service provision acted in a range of ways to ensure the continuity of services and support, and to advocate for better and more targeted funding for services which are core to independent living.

The reality is, disability services were already underfunded and understaffed in many countries and the COVID-19 pandemic basically brought disability services to their knees.

- **ARFIE**[370] works with people with intellectual disability and needed to bring its work online – an intense commitment from persons with intellectual disabilities and their families to take part in online focus groups.

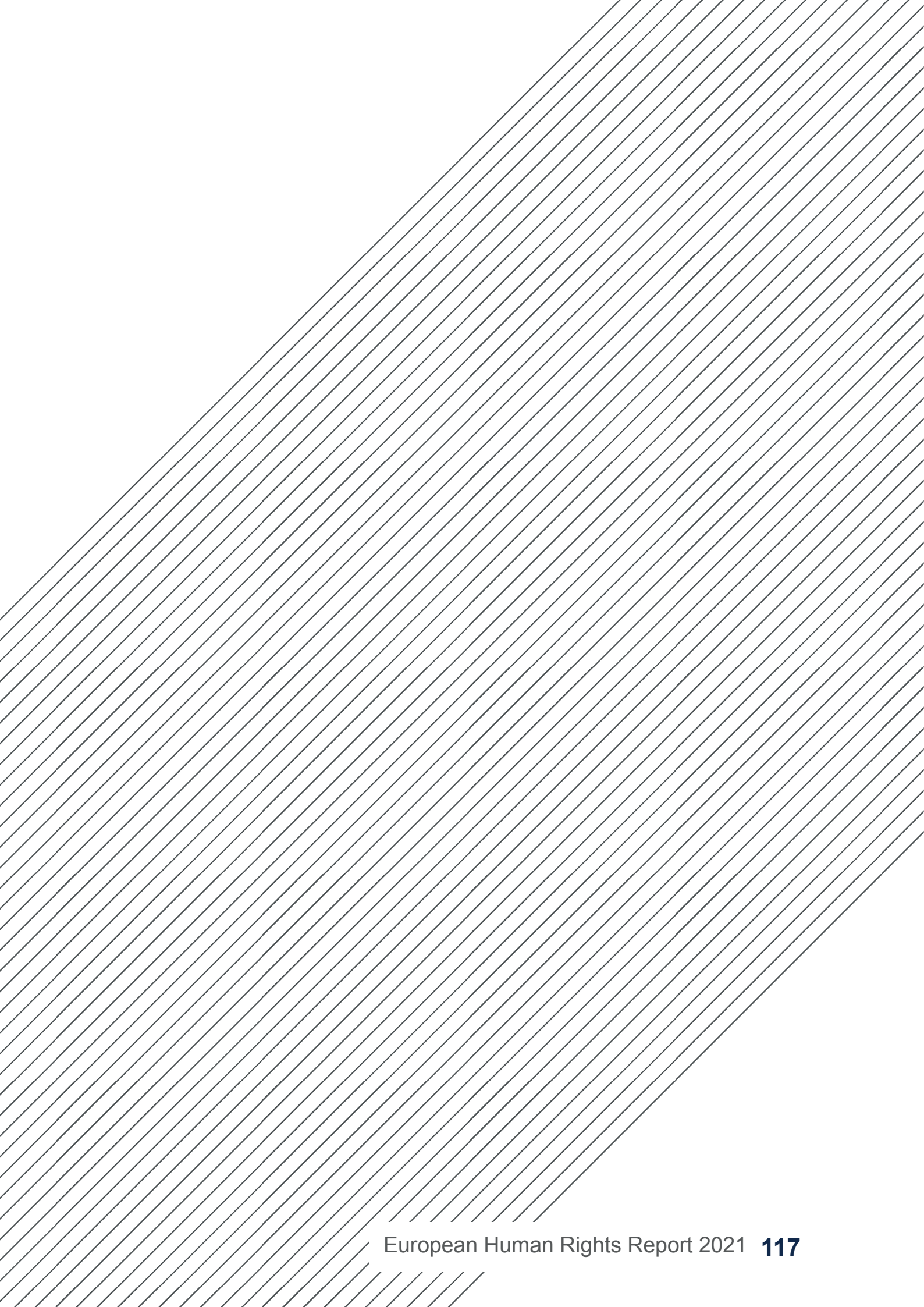
- The **European Association of Service Providers for Persons with Disabilities** (EASPD) brings together disability service providers who were immediately heavily impacted both by the pandemic and all of the lockdown measures which left services without staff, without personal protective equiment, and excluded from the support which governments have targeted towards businesses. EASPD ran a series of online meetings for its members to share and learn how to cope with COVID-19. They worked with alliances, including with social service providers, to campaign at the EU level for more funding to reach disability services so that they can rebuild, function, recruit and train staff, and ensure staff and service users are adequately protected from COVID-19[371].

Equality bodies and Human Rights Institutions

Equality bodies and National Human Rights Institutions have been instrumental in collecting complaints of people with disabilities and documenting human rights violations during the pandemic.

At the European level, for instance, the national network of equality bodies, **Equinet**, launched an online database[372] to track impact on equality of COVID-19 with information from equality bodies in 26 countries across Europe. The **CRPD Working Group of the European Network of National Human Rights Institutions**[373] held meetings to discuss issues happening in the countries of their members and actions taken to support persons with disabilities.

These bodies have also been active in advocating for disability rights at the national level. For example, in **Belgium**, Unia, the Interfederal Centre for Equal Opportunities collected discrimination complaints and raised concerns to the government about access to health, the accessibility to supermarkets, and the lack of assistance for persons with disabilities on trains[374]. The Ombudswoman for Children of **Croatia** published recommendations for the protection of the child's best interest in distance learning, with specific recommendations regarding children with disabilities[375].



Conclusions and Recommendations

While the EU and all European countries (except Liechtenstein) have ratified the CRPD, their policy and institutional approaches to the rights of persons with disabilities 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.

The absence of disability-related data is a stark example of the 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.

The level of death in institutions and other closed settings is a tragedy that even initial gaps and oversight in monitoring could not hide. We have been shocked and ashamed by the deaths of older persons and persons with disabilities in these facilities. We have been appalled by the increase of violence against women, in and out of institutions. 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.

The neglect of persons with disabilities throughout the COVID-19 pandemic highlights the lack of willingness and/or capacity of governments to take action to protect the rights of persons with disabilities and implement the CRPD. It shows the lack of horizontal mainstreaming of the rights of persons with disabilities in all areas that affect their lives and has shone a light on the marginalisation in which so many persons with disabilities live in Europe.

Persons with disabilities living in other parts of the world face similar challenges, sometimes on a greater scale. All of the following recommendations therefore apply equally to EU external action, including international partnerships and humanitarian activities.

One strength that the crisis has shown is that of the disability movement, including representative organisations of persons with disabilities and persons with disabilities themselves. Their response was immediate and robust. This demonstrates the important role played by organisations of persons with disabilities and the need to strengthen their capacity.

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. Some governments responded to advocacy from organisations of persons with disabilities, others did not or did so in a limited fashion. 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 from the start of the response to the pandemic 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 over the course of this year, 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 in 2020. In addition, persons with disabilities continue to face immediate socio-economic challenges that need urgent redress.

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. **Political commitment and investigation:** to ensure the rights of persons with disabilities at all time, including in situations of risk and humanitarian emergencies such as the COVID-19 crisis, and to investigate the impact of the governments' response on persons with disabilities. This can ensure that the same mistakes will not be repeated in future crises.
2. **Consultation and involvement:** Adopt measures to ensure systematic involvement of all persons with disabilities through their representative organisations in all decisions that affect their lives, and include the most disadvantaged groups, including self-advocates. This requires to ensure adequate funding for representative organisations of persons with disabilities.
3. **Preparedness and response:** Invest in a disability-inclusive process of preparedness to prevent the devastating impacts of future crises and ensure inclusive crisis response. Such a response must include accessible public health announcements and emergency communication. It must also include targetted actions to support persons with disabilities. This includes ensuring specific resources are allocated to make mainstream services inclusive and accessible, including for example vaccination programmes, employment, prevention of violence measures, emergency communications, etc.
4. **Disaggregated data:** Ensure that all data collected is disaggregated by age, gender, and disability. Persons with disabilities living in institutions and other 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.

6. **Accessibility and inclusion:** Ensure accessibility and inclusion of persons with disabilities at all levels of governance, information, response and recovery measures, service-provision, and in society. The impact of COVID-19 on European economy should not lead to deprioritsation of investment in accessibility of information and communications technologies, transport and other services, and built environment.
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:** Underpin all actions with a human rights approach and the CRPD:
    - » Ensure equality and non-discrimination in legislation and practice for all persons with disabilities.
    - » Protect persons with disabilities from violence, abuse, exclusion, coercion, and neglect, with disability, gender, and age-sensitive actions.
    - » Ensure continuous, independent human rights monitoring.
    - » Ensure free and informed consent is guaranteed prior to vaccination
10. **Women's rights:** Ensure 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 exit measures for transport services in light of COVID-19 (May 2020)

Our recommendations on vaccination (October 2020)

Learning for the disability movement

We have concentrated one chapter of this report on the role the disability movement has played during the COVID-19 pandemic in 2020, with a focus on what our members have done. It is also not a surprise to say that this is a year when we have learned a lot – learning while doing. We need to be prepared for a completely altered future, in Europe and globally. We ourselves and our members need to reflect on these points. We need to focus on different areas:

- **Our working methods and our resources:** We had to completely change our way of working in 2020. These changes were abrupt and unprepared for. We need to ensure we always have the ability and resources to react and adapt.
- **Partnerships**: To be effective, we need to collaborate with others – we need to invest in partnership. We should reach out to work with those creating policies in health, in preparedness, in the labor market, in education, etc., to ensure they can and will build systems and policies that are inclusive and accessible to all persons with disabilities, including those with multiple identities.
- **Intersectionality:** It was clear and demonstrated in this report that many people with disabilities fall through the cracks of governments' planning, and our own responses, because of intersectional forms of discrimination. We need to build on our cooperation and interactions with other minority and disadvantaged people so that we can speak with one voice in advocating for a Europe of equality.
- **The importance of meaningful participation**: A major gap in government actions in 2020 was the lack of systematic involvement of persons with disabilities through their representative organisations. The motto of our movement, 'nothing about us without us', was not in action at the onset of this pandemic, for the most part, in Europe. We need to advocate for better involvement. We need also to strengthen our own movement so our members can be strong, sustainable, and united in our diversity and be fully involved in all decisions that affect the lives of all persons with disabilities.
- **Preparedness:** COVID-19 crisis planning did not include us. We need to be included in resilience planning at the EU and national levels.

- **Looking ahead:** Be aware of the global changes in the economy, and in society. All these changes will affect us, and our members. We should be part of the change, so a new, more inclusive world evolves from COVID-19.

Concerns for the future

The crisis is not over. This report only covers the impact of COVID-19 in 2020. As we publish this report in early 2021, European countries are still increasing lockdown measures in the hopes of curbing infection and death rates. New strains of the virus are emerging. Vaccination roll-outs are starting but with many pitfalls and without the explicit inclusion of persons with dsabilities and involvement of their representative organisations. EDF will follow these developments closely so that persons with disabilities can access vaccination (on a free and informed consent basis) and come back to leading their lives through full inclusion in the COVID-19 recovery plans.

But we do not just want the pre-COVID reality of stagnating socio-economic well-being, lack of accessibility, institutionalisation, and discrimination. We wish to work with our partners and allies in rebuilding and reshaping Europe and the world, to build back better and more inclusive.

EDF is concerned about the economic downturn Europe and the world is facing. Based on our experience in the last economic crisis, with persons with disabilities hit so harshly by austerity measures, we need to advocate for funding, for investment, and for being part of the economic recovery. The rights of person with disabilities, such as inclusive employment, education, social protection, and accessibility should be invested in, not made the subject of cutbacks.

COVID-19 lockdown measures have unfortunately caused restrictions in our ability to organise, to protest, to gather in groups, and advocate for our rights. These restrictions should only last as long as needed to control the virus. Once COVID-19 has passed us, these restrictions should be ended so we can participate in public debate, gather and organise, and protest for a stronger, more inclusive Europe.

This crisis has brought our priorities into focus and given us a strong motivation to redouble our efforts to make the CRPD a reality in the daily lives of all persons with disabilities.

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