

Accessible disability-inclusive information during COVID-19

European Disability Forum Position Paper

By Mundo Madou | January 2021

**A short guidance note for organizations of persons with disabilities (DPOs) in the WHO Europe region.**

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# Introduction

### The European Disability Forum

The European Disability Forum is an independent NGO that represents the interests of 100 million Europeans with disabilities. EDF is a unique platform which brings together representative organisation of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

### Acknowledgements

Thanks to all who participated in the drafting of this position paper.

## Executive Summary

This paper serves to provide guidance on ensuring the effects of COVID-19 on people with disabilities are addressed. It also serves as a short technical support to organizations of persons with disabilities (DPOs) on accessible disability-inclusive information. EDF has also produces another guidance note, to guide health ministries.

# Easy to Read

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| The Easy to Read logo. An image of a person smiling behind an open book. | | This page is about **recommendations to European health ministries regarding COVID-19 and the rights of persons with disabilities** in Easy to read. |
| This paper serves to provide guidance on ensuring the effects of COVID-19 on people with disabilities are addressed. | | |
| It also serves as a short technical support to health ministries on accessible disability-inclusive information. | | |
| EDF has also produces another guidance note, to guide organizations of persons with disabilities (DPOs). | | |
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# Background information

The COVID-19 pandemic has highlighted systemic failures to consistently include persons with disabilities in global crisis response. While all [53 World Health Organization (WHO) European Members States](https://www.euro.who.int/en/countries) have ratified the [UN Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext) (CRPD), their policy and institutional approaches to the rights of persons with disabilities often remain ad hoc and can contribute 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 an afterthought in government actions that turned lives upside down. The lack of timely access to relevant information about prevention and treatment of COVID-19 and, the availability of support, has greatly contributed to the disproportionate impact of the pandemic on persons with disabilities and their families.

The [WHO Regional Office for Europe](https://www.euro.who.int/en/home), in collaboration with the [European Disability Forum](https://www.edf-feph.org/) (EDF), aims to provide practical resources to organisations of persons with disabilities (DPOs), to support their advocacy, for the realisation of the right of access to information by persons with disabilities, during the COVID-19 pandemic. With financial support from the WHO Europe, EDF has created the following two videos:

* Video 1: <https://www.youtube.com/watch?v=fUg5uq-7aPc&t=1s>
* Video 2: <https://www.youtube.com/watch?v=uVxt2jvuvXU>

This guidance note compliments the videos and serves as a short technical support to DPOs on accessible disability-inclusive information. EDF has also produced another guidance note supporting health ministries in the WHO European region.

# Overview: The “gold” standard

COVID-19 related information must be produced using the principle of **Universal Design**. This means that all general, and disability-specific information, is presented in a clear, accessible, and relatable manner in a diverse range of digital and non-digital formats, that are used by different members of the population. This information also needs to be easy to find.

Persons with disabilities must have access to the same amount and quality of information as non-disabled people, including live news. Features such as accessibility for screen readers, interpretation into the national sign language, easy-to-read and plain language, captions and Braille must be present throughout, depending on the medium. Persons with disabilities in institutional settings must have direct access to information on an equal basis with others. When persons with disabilities have equal access to information, they are empowered to make decisions based on their free and informed consent.

# Four priority areas for short- and long-term interventions to facilitate the accessibility and inclusiveness of public information

## Accessibility of emergency communications and public health information

Persons with disabilities have reported that COVID-19 related digital communications in their countries is inaccessible, excluding them from timely access to potentially life-saving information about testing, treatment and vaccination. Persons with disabilities, including persons who are deaf, hard of hearing, have speech impairments, are blind or deafblind, as well as persons with intellectual and psychosocial disabilities, continue to be at risk of exclusion in relation to potentially life-saving emergency and essential support telephone numbers.

Whilst the responsibility to ensure accessibility of emergency communication lies with the authorities, during this pandemic it has been the disability organisations that have provided the communication support in many countries, often with little or no financial support from the government.

**Recommendations for the short term:**

* Advocate for strong transposition and effective implementation of European accessibility legislation, such as the [Audiovisual Media Services Directive](https://www.edf-feph.org/audiovisual-media-services-directive/), [European Accessibility Act](https://www.edf-feph.org/content/uploads/2020/12/final_edf_transposition_toolkit_accessibility_act.pdf), [European Electronic Communications Code](https://www.edf-feph.org/electronic-communications/), and the [Web Accessibility Directive](https://www.edf-feph.org/web-accessibility-directive/) which requires public sector bodies across Europe to have accessible websites and mobile applications.
* Disseminate and advocate for the **use of simple and accessible guidelines,** developed by the global disability community, such as [10 Rules to Improve Web Accessibility](https://www.edf-feph.org/web-accessibility/), [Making Information Accessible for All](http://www.euroblind.org/publications-and-resources/mak) or [Easy-to-read Checklist](https://www.inclusion-europe.eu/wp-content/uploads/2020/06/Easy-to-read-checklist-Inclusion-Europe.pdf).
* Encourage all stakeholders engaged in the COVID-19 response to **make their digital information and communication accessible for all persons with disabilities**. This especially concerns emergency and primary healthcare services; providers of essential support services, such as social support, mental health support, support for victims of violence and abuse; educational establishments. We especially highlight the need for accessible information for persons with disabilities who are deprived of liberty in institutions and psychiatric settings.
* Advocate for the **use of an indicator on the accessibility of information and communications into the national human rights monitoring processes**; alert the national human rights institution or CRPD monitoring body of the life-saving importance the accessibility of information and communication for the disability community.
* Advocate for **accessible emergency information,** made available to the public through audiovisual media services, including public communications and announcements in natural disaster situations or other emergencies. This means ensuring the provision of access services, such as subtitles for persons who are deaf and hard of hearing, sign language interpretation, audio-description, and others as required following minimum standards for quality of these services. Highlight that The [European Audiovisual Media Services Directive (AVMSD)](https://www.edf-feph.org/audiovisual-media-services-directive/) requires Member States to “ensure that emergency information, including public communications and announcements in natural disaster situations, which is made available to the public through audiovisual media services, is provided in a manner which is accessible to persons with disabilities.”
* In EU countries, advocate for Public Safety Answering Points (PSAPs) for the emergency number ‘112’ to **comply with the accessibility and interoperability requirements** of the European Accessibility Act for PSAPs, responding to emergency calls by real-time text and total conversation services. National emergency numbers and dedicated numbers for providing COVID-19-related information and services should use the same requirements.
* Advocate that public warnings, emergency information and communications are **accessible through more than one sensory channel** (for example text **and** audio) and easy to understand. Clear, easy to follow instructions for behaviour should follow (for example, stay inside, do not open windows, etc.). Pictograms can make the information accessible for viewers who might not understand the language, or persons with cognitive disabilities.
* Advocate for the **establishment of remote relay services for persons who are deaf and hard-of-hearing**, facilitated by qualified sign language interpreters and palantypists. Organisations of persons with disabilities who provide such a service must be compensated adequately.
* Provide persons with disabilities in your constituency with **clear succinct instructions on how to contact emergency services in case of a need**.

**Recommendations for the long term:**

* **Build a campaign** to advocate for the development of a national web accessibility standard, based on universal design and inspired by the international [Web Accessibility Content Guidelines (WCAG)](https://www.w3.org/WAI/standards-guidelines/wcag/). The standard should be linked to legislation making its implementation compulsory and introducing dissuasive sanctions when it is not respected.
* In EU countries, **advocate for the accessibility** of the single European union emergency number 112, national emergency numbers, public health communication and other essential support services (such victim support line, missing children -116000- and child helpline -116111-, etc) to be provided in national legislation, in line with the national obligations under the articles 9 (accessibility) and 21 (freedom of expression and opinion, and access to information) of the CRPD and the [Electronic Communications Code](https://www.edf-feph.org/electronic-communications/) and [European Accessibility Act](https://www.edf-feph.org/content/uploads/2020/12/final_edf_transposition_toolkit_accessibility_act.pdf).
* In EU countries, advocate for the **deployment of Advanced Mobile Location (AML) systems for calls and text to the single European emergency number ‘112’** and national emergency numbers effectively and without undue delays. This is a technology that allows locating the person making the emergency call or sending the emergency text by identifying the location of the device they used for emergency communication.
* **Advocate for deployment of Next Generation ‘112’** to enable high quality accessible emergency communication using real-time-text and total conversation services over internet protocol.

**Useful resources:**

* [Clear print guidelines](http://www.euroblind.org/publications-and-resources/guidelines)
* [COVID-19 and persons with psychosocial disabilities](http://enusp.org/wp-content/uploads/2020/04/COVID19-and-persons-with-psychosocial-disabilities-final_version-1.pdf)
* [CRPD General Comment No 2 on Accessibility](https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/033/13/PDF/G1403313.pdf?OpenElement) available in all official UN languages.
* [CRPD Committee Concluding Observations](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD) to your country, if it has already been reviewed by the Committee
* [EDF toolkit on transposition of the European Accessibility Act](https://www.edf-feph.org/content/uploads/2020/12/final_edf_transposition_toolkit_accessibility_act.pdf)
* [Directive on accessibility of the websites and mobile applications of public sector bodies. Toolkit of organisations of persons with disabilities](https://www.edf-feph.org/content/uploads/2020/12/final_edf_web_and_apps_directive_toolkit_may_2017_0.pdf)
* [European Electronic Communications Code: Toolkit for transposition](https://www.edf-feph.org/content/uploads/2020/12/edf_toolkit_on_transposition_of_the_european_electronic_communications_code5231.pdf) prepared by the European Disability Forum
* EDF [recommendations on equal access and choice to electronic communications](http://www.edf-feph.org/content/uploads/2020/12/edf_recommendations_on_equal_access_and_choice_to_electronic_communications_services_1_1.pdf)
* [EDF toolkit on transposition of the European Audiovisual Media Services Directive](https://www.edf-feph.org/content/uploads/2020/12/final_edf_avmsd_toolkit_november_2019_0.pdf)
* [European Standard on Accessibility requirements for ICT products and services (EN 301549)](https://www.etsi.org/deliver/etsi_en/301500_301599/301549/03.01.01_60/en_301549v030101p.pdf)
* European Disability Forum and its members’ advocacy around accessible emergency number 112

## “Nothing about us without us”: the role of representative organisations of persons with disabilities in COVID-19 response and recovery.

Representative organisations of persons with disabilities are best placed to advise on how to identify the most excluded persons with disabilities in their community, and share information about COVID-19. It is an obligation under the UN Convention on the Rights of Persons with disabilities for all regional, national and local governments to consult, and meaningfully involve, persons with disabilities, through their representative organisations, in all decisions regarding COVID-19 response and recovery, making sure their suggestions are considered and taken onboard. This includes ensuring providing adequate funding for representative organisations of persons with disabilities.

**Recommendations for the short term:**

* **Demand to be involved in all regional, national and local government COVID-19 response coordination meetings** with concrete proposals demonstrating the added value of systematic partnerships with DPOs. Highlight that all meeting information, documents, platforms for communication, online and offline meetings must be accessible for all persons with disabilities (e.g. using platforms which are accessible to screen readers, ensuring sign language interpretation for deaf participants, hiring real time captioners, providing documents in easy to read format, etc. when having online meetings).
* **Approach international organisations** present in your country, including the WHO, to ensure that their COVID-19 activities are disability-inclusive and accessible.
* If your country has ratified the CRPD and undergone the first round of reviews by the CRPD Committee, it most certainly received a recommendation to involve DPOs in all relevant work. **Use these recommendations to demand involvement in all COVID-19 response and recovery actions.** You will find additional arguments on participation in the [CRPD General Comment No. 7](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2pjFYzWLBu0vA%2bBr7QovZhbuyqzjDN0plweYI46WXrJJ6aB3Mx4y%2fspT%2bQrY5K2mKse5zjo%2bfvBDVu%2b42R9iK1p) available in all official UN languages.

**Recommendations for the long term:**

* **Advocate to government for funding and capacity building** to become effective partners in developing COVID-19 responses that are inclusive and accessible.
* **Strengthen the disability movement to be sustainable and united** in its diversity and be fully involved in all decisions that affect the lives of all persons with disabilities.
* **Develop a training course** on accessibility of public health information and communication for persons with disabilities.

**Useful resources:**

* [International Disability Alliance accessibility campaign with letters received from UN Secretary-General, UNFPA, UNHCR](https://www.internationaldisabilityalliance.org/acessibility-campaign)
* [UNICEF. COVID-19 response. Considerations for Children and Adults with Disabilities](https://www.internationaldisabilityalliance.org/sites/default/files/covid-19_response_considerations_for_people_with_disabilities_190320.pdf)
* [WHO. Disability considerations during the COVID-19 outbreak](https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1)
* [OHCHR. COVID-19 and the rights of persons with disabilities. Guidance.](https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf)
* European Disability Forum:
  + letter to EU Commissioner for Health Stella Kyriakides
  + statement “Persons with disabilities stripped of support and protective equipment during COVID 19 crisis”
  + statement “Residential institutions are becoming hotbeds of infection and abuse – governments need to act now”
  + open letter “COVID 19 – medical guidelines should not discriminate against persons with disabilities”
  + EDF members’ activities on COVID-19

## Free, informed and explicit consent

All decisions concerning a person’s testing, treatment or forthcoming vaccination against COVID-19 must be made in accordance with the person’s explicit free, and informed consent. For persons with disabilities this means, firstly, access to objective and clear information about the planned intervention with the possibility to ask questions in their preferred format. This information should be made continuously available upon the person’s request to facilitate retention of information. Secondly, this means that the person should be empowered to make the decision themselves – either independently or with support from another person(s). Persons with disabilities deprived of their legal capacity or living in institutions are often prevented from making informed decisions about their lives.  When providing information about their health and disability to access health-care and vaccination against COVID-19, persons with disabilities should be made adequately aware of how their data is being stored, used and processed. This should be done strictly in line with country data protection rules.

**Recommendations for the short term:**

* **Work with healthcare providers** to ensure that the information about COVID-19 testing, treatment and vaccination is available in diverse accessible formats, including easy-to-read, and that it reaches all persons with disabilities, including those in residential settings. The availability of a feedback loop is essential: all persons with disabilities must be able to ask questions or clarifications before making decisions.
* **Offer your expertise to facilitate communication** about COVID-19 testing, treatment and vaccination to healthcare providers to ensure that persons with disabilities are able to make their free, and informed decision about their course of treatment or vaccination.
* **Develop and disseminate communicational support tools**, similar to this [COVID-19 Communication Rights Toolkit](https://communicationfirst.org/covid-19/), to be used in healthcare settings by persons with disabilities if they wish to do so.

**Recommendations for the long term**

* **Advocate for a reform of legal capacity legislation** to replace the regime of substituted decision-making with a system of supported decision-making in accordance with article 12 of CRPD (equal recognition before the law) and the [CRPD Committee General Comment No 1 on equal recognition before the law](https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement).
* **Start developing and rolling out innovative models of decision-making support** that is based on the choice and preferences of the person with disabilities.

**Useful resources:**

* [Mental Health Europe position paper and video clip on legal capacity](https://www.mhe-sme.org/legalcapacity/)

# About EDF

The [European Disability Forum](https://www.edf-feph.org/) is an **independent NGO that represents the interests of 100 million Europeans with disabilities.** EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

# About WHO Europe

The World Health Organization (WHO) is the authority responsible for public health within the United Nations system. The [WHO Regional Office for Europe](https://www.euro.who.int/en/about-us) (WHO/Europe) is one of WHO’s six regional offices around the world. It serves the WHO European Region, which comprises 53 countries, covering a vast geographical region from the Atlantic to the Pacific oceans. WHO/Europe staff are public health, scientific and technical experts, based in the main office in Copenhagen, Denmark, in 3 technical centres and in country offices in 30 Member States.

# Further reading

* WHO (May 2020): [Policy Brief of the UN Secretary-General: A Disability-Inclusive Response to COVID-19](https://www.who.int/publications/m/item/policy-brief-of-the-un-secretary-general-a-disability-inclusive-response-to-covid-19)
* WHO (2020): [Disability considerations during the COVID-19 outbreak](https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1)
* WHO/Europe (2020): [Support for rehabilitation self-management after COVID-19-related illness](https://www.euro.who.int/en/health-topics/Life-stages/disability-and-rehabilitation/publications/support-for-rehabilitation-self-management-after-covid-19-related-illness-2020-produced-by-whoeurope)
* WHO EMRO (2020): [Regional technical brief on ‘Protecting people with disability during the COVID-19 pandemic](http://www.emro.who.int/health-topics/corona-virus/technical-guidance-notes.html?format=html) (available in Arabic and English)
* WHO (2020): [Summary report on considering disability in COVID-19 hygiene programmes](https://resources.hygienehub.info/en/articles/4097594-summary-report-on-considering-disability-in-covid-19-hygiene-programmes)
* EDF (2021): [Human Rights on COVID-19](https://www.edf-feph.org/human-rights-report-2021-covid19/)
* EDF (updated daily):  [Resources](http://www.edf-feph.org/covid19) on COVID-19
* EDF (2021): [WHO Europe’s regional leadership engages to reinforce inclusion of persons with disabilities in the COVID-19 response](https://www.edf-feph.org/world-health-organisations-regional-leadership-engages-to-reinforce-inclusion-of-persons-with-disabilities-in-the-covid-19-response/)

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This publication has received financial support from the World Health Organization Regional Office for Europe (WHO). The information contained in this publication does not necessarily reflect the official position of the WHO Regional Office for Europe.

