



EDF recommendations on the European Health Union Package

European Disability Forum

info@edf-feph.org | +32 2 329 00 59

Mundo Madou, Avenue des Arts 7-8, 1210 Brussels, Belgium

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About the European Disability Forum

The European Disability Forum (EDF) is an umbrella organisation of persons with disabilities that defends the interests of over 100 million persons with disabilities in the European Union. We are a unique platform which brings together representative organisations of persons with disabilities from across Europe. We are run by persons with disabilities and their families, and as such represent a strong, united voice of persons with disabilities in Europe. Specific expertise on gender and women's rights issues is provided by EDF Women's Committee. EDF is committed to the women's movement and an active member of the European Women's Lobby.

Introduction

The European Union and all its Member States have ratified the **United Nations Conventions on the Rights of Persons with Disabilities (CRPD)**. This international treaty creates specific obligations relevant for the EU and all Member States in the creation of the European Health Union Package.

Under **article 25 of the CRPD**:

States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

In addition, according to **article 11 of the CRPD** States parties must take “all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”

Persons with disabilities were one of the most affected groups of the COVID-19 pandemic in the European Union, in term of contamination, deaths and human rights violations. The EC proposals which are part of the European Health Union Package must ensure that the EU and Member States are better equipped to activate a disability inclusive response to future health threats and pandemics.

The European Disability Forum, umbrella organisation of persons with disabilities defending the rights of over 100 million persons with disabilities in the EU, run by persons with disabilities and their families calls on the European Commission to incorporate the rights of persons with disabilities in its 3 proposals for regulations part of the European Health Union Packages.

Recommendations

1. **Nothing about us, without us (art. 4.3 CRPD)**: persons with disabilities through their representative organisations must be adequately consulted and actively involved in the development of the European Health Union Package, and in the response to all future health threats and pandemics. Expert groups created as part of the new package on health should also include organisations representing the most severely affected people concerned by the specific health threat,

which will vary depending of the nature of the health crisis. Where persons with disabilities are disproportionately affected, there should be a means for them to meaningfully participate.

2. **Right to life (art. 10 CRPD):** protecting the right to life to all persons living in the EU, including persons with disabilities, must be a core objective of the European Health Union Package, from prevention and preparedness, testing, treatment and vaccination. Part of foreseeing responses to future health crises will therefore require ensuring that the response is adapted to the needs of persons with disabilities. This means ensuring that medicines and devices developed in response to a health crisis can be used by all, and that particularly high-risk groups should be prioritised in the distribution of vaccines. It also means that plans for an EU-wide coordination of emergency care must be done in a way that will not see persons with disabilities denied treatment on the basis of disability .

3. **Preparedness and response (art. 11 CRPD):** The European Union and its Member States must ensure that all emergency preparedness measures are fully inclusive. These obligations are affirmed by the [Sendai Framework for Disaster Risk Reduction](#) (2015-2030), implementation of which the EU monitors through its [Action Plan on the Sendai Framework for Disaster Risk Reduction](#) and the [Charter on Inclusion of Persons with Disabilities in Humanitarian Action](#) (2016), to which the EU and 14 of its Member States are signatories. For practical implementation, they are further supported by [DG ECHO Operational Guidance - The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations](#) (2019) and the [UN IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action](#) (2019).

4. **Accessibility (art. 9, CRPD):**
 - a. **Emergency public information and communications:** COVID-19 has demonstrated gaps in ensuring accessibility of **public emergency information** for persons with disabilities. This includes providing emergency information through public broadcasting, but also via written or other means in dedicated websites, mobile apps and digital platforms. The EU Health Package should be in consistent with EU policies and legislation

to ensure persons with disabilities have equal access to technologies and information required during public health emergencies.

- The **European Audiovisual Media Services Directive (AVMSD)** requires that emergency information made available to the public through audiovisual media services, including public communications and announcements in natural disaster situations or other emergencies is accessible for persons with disabilities. This means ensuring provision of access services such as subtitles for the deaf and hard of hearing, sign language interpretation, audio-description, and others as required following national protocols and minimum standards for quality of these services.
- The **Web Accessibility Directive** requires public bodies to have websites and mobile apps which are accessible for persons with disabilities following the harmonized [European Standard EN 301 549 on accessibility requirements for ICT products and services](#). Thus, all health initiatives making use of digital means (including “eHealth” applications) should respect this European accessibility standard.
- The **European Electronic Communications Code (EECC)** requires Member States to ensure accessibility of telecommunications services, including accessibility of the single European emergency number ‘112’. In this domain, COVID-19 also showed that in many countries, inaccessible emergency numbers meant that, some people who are deaf, hard of hearing, blind or deafblind, with intellectual and psychosocial disabilities or with speech impairments, were prevented from communicating with potentially life-saving emergency and essential support services.
- The **European Accessibility Act (EAA)** sets minimum accessibility requirements for digital and other services and products, including for accessibility of technologies which are important for emergency communication and information (e.g. mobile apps, laptops, software, etc.). An important requirement for the EAA is that dedicated answering centers for emergency services (PSAPs) ensure accessible communications for persons with disabilities (e.g. by use of

real-time text and total-conversation technologies). Furthermore, the Accessibility Act lays down a set of functional accessibility requirements in its Annex I which can be useful for the procurement of accessible products, services (including information), and built environment. The reference and use of these common accessibility requirements will ensure an adequate level of accessibility in all health initiatives too.

- b. **Information systems:** Digitalisation process should ensure that development of new technologies to tackle public health emergencies are accessible for persons with disabilities. In addition to the legal requirements mentioned above, the [European Standard on accessibility of ICT products and services \(EN301 549\)](#) should be followed for technical guidance, and the ['Design for All - Accessibility following a Design for All approach in products, goods and services - Extending the range of users' \(EN 17161:2019\)](#) can be adopted by any kind of organisation to ensure the result of their activities are accessible for persons with disabilities.
- c. **Labeling of medical devices**, including protective equipment, sanitary products should be accessible for persons with disabilities. Protective equipment design should also take into account different access needs of persons with disabilities (e.g. transparent masks for hard of hearing, deaf or other persons who use lip-reading for communication is important).
- d. **Cost:** As well as foreseeing the availability of medicines and devices in the EU, the package also needs to work to ensure their affordability to all. This is a particularly pressing issue given that groups such as persons with disabilities, who are typically at higher risk during health crises, are already far more likely to have low incomes and high outgoings¹. This makes persons with disabilities far more prone to poverty and social exclusion and thus less likely to be able to afford costly medicines or devices. A

¹ https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF_HR_Report_final_tagged_interactive_v2_accessible.pdf

strategy that overlooks the issue of cost could risk underserving the most at-risk during the next pandemic.

5. **Equality and non-discrimination (art. 5 CRPD):** relevant initiatives under the Package must aim at combating human rights violations faced by discriminated groups such as persons with disabilities, including women and children with disabilities as required by the CRPD and the Sendai Framework for Disaster Risk Reduction. Despite obligations under the CRPD and the Charter on Fundamental Rights of the European Union, the EU law fails to prohibit disability-based discrimination in the field of health. The European Centre for Disease Prevention and Control should have an enhanced role in identifying the most at-risk people and ensuring their inclusion in data and in recommendations and guidelines. The proposed EU Regulations must comply both with the EU Charter on Fundamental Rights and the CRPD.

6. **Data collection and disaggregation (art. 31 CRPD):** data collected must be disaggregated by age, gender and disability as required by the CRPD and the Sendai Framework for Disaster Risk Reduction. Currently, data are not disaggregated, or when they are, data of persons with disabilities living in closed settings such as institutions are not collected. In the meantime, privacy of persons with disabilities should be respected in accordance to EU data privacy law.

7. **The EU in the World (art. 32 CRPD):** Through effective international partnerships with GAVI and the WHO for instance, the EU and its member states must ensure equitable access to testing, treatment and vaccination for persons with disabilities in countries with less robust healthcare systems and economies. They must also speed-up the delivery of vaccine delivery not just in Europe but also in the world. The EU must advocate for the COVAX initiative to prioritise persons with disabilities since “Team Europe” contributed €500 million to COVAX to provide one billion COVID-19 vaccines doses in December 2020. The countries the most in need to receive support from COVAX are 92 countries that cannot afford to buy vaccines on their own. They are also countries where often persons with disabilities are viewed as second-class citizens and where their rights are systematically denied and violated. The new [suggested EU mechanism](#) by Commission President

Ursula von der Leyen where member countries could donate doses to the global south should ensure the prioritization of persons with disabilities. The new EU set-up was announced on 21st January 2021 during the [COVID-19 conference](#) of the members of the European Council. The principle expressed in the EUs vaccination strategy- that the COVID 19 vaccination is a public good, and should available free to all should also be born our in the EUs global approach.

Contact person at the EDF secretariat

Marine Uldry, Human Rights Officer: marine.uldry@edf-feph.org

Should you have any problems in accessing the documentation, please contact the EDF Secretariat. (Tel: +32 (0)2 329 00 59, Email: info@edf-feph.org).