

UNCRPD implementation and ratification of the Optional Protocol

The topics for discussion are as follows:

- CRPD implementation and National Parliaments monitoring role
- examining the need for a standard definition of disability
- Ratification and pathway to enacting of the Optional Protocol
- Disability and the Sustainable Development Goals
- safeguarding and confidentiality of data collection and processing
- Ensuring a disability inclusive response to Covid-19 (Articles 1–4, 11, 18, 22, 31, 32, 33)

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Introduction to EDF

- EDF umbrella organisation representing persons with disabilities in the EU with members at the national level and European level across Europe
- Our work is advocating for the rights of persons with disabilities
- EDF is also part of the independent monitoring framework established by the EU to monitor the CRPD at the EU level, together with the EUs Fundamental Rights Agency, the European Ombudsman and the European Parliament.
- We publish information for our members on [their rights in the EU](#), and we have a regular Human rights report series assessing the extent to which the CRPD is being implemented in Europe- last years report focussed on [COVID 19 and persons with disabilities](#) and highlighted the neglect and discrimination faced by Europe's 100 million persons with disabilities last year as the pandemic ravaged Europe.

CRPD implementation and National Parliaments monitoring role

While it was disappointing that Ireland was the last EU member state to ratify the CRPD, it is inspiring to see the leadership now been shown in Ireland through the establishment of this Committee.

This committee demonstrates the vital scrutiny role that National Parliaments can play.

Shortly after the coming into force of the CRPD, the UN published a guidebook, for Parliaments on their role in the CRPD¹. Parliamentary committees were described as an important measure. Not enough countries have established Parliamentary committees.

Parliamentary oversight complements the monitoring and coordination functions set up through the CRPD- monitoring, and coordination of actions are critically important to success. This committee does not stand alone of course, and every other committee which follows a department also should be playing this scrutiny role. For example, if your committee on foreign affairs is working on the SDGs- then this is also where inclusion and accessibility for persons with disabilities in Irelands SDG programme will be handled.

Your committee will hold Ministers and Civil servants to account related to implementation of the CRPD, and for example the allocation of resources to its implementation, but will also have the opportunity to discuss these matters with visiting EU officials.

Ratification and pathway to enacting of the Optional Protocol

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, so it is important that Ireland moves ahead with ratification.

It also allows the CRPD Committee to make an [inquiry](#) in case of serious, grave or systematic violations of the CRPD in a State party.

Twenty-two EU Member States, as well as all EU candidate countries and the United Kingdom have ratified the Optional Protocol. The CRPD Committee has consistently called States Parties, in particular in its concluding observations, to ratify the Optional Protocol.

In our regulation human rights report 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.

This is an important measure of a States Parties willingness to be held to account and to enable your citizens to seek redress.

¹ (<https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html>)

Notably on the role of Parliament:

<https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-seven-creating-national-institutions-to-implement-and-monitor-the-convention-4.html>

Disability and the Sustainable Development Goals

Inclusion is at the core of the 2030 Agenda for Sustainable Development, with its promise to “leave no one behind” but also “to reach the furthest behind first”. Unlike the previous Millennium Development Goals, **disability issues and persons with disabilities are included** with 11 specific references throughout the 2030 Agenda. Overall, the 17 Sustainable Development Goals (SDGs) contain 169 targets and 231 indicators for monitoring the implementation of the 2030 Agenda. Persons with disabilities are mentioned **19 times in the SDGs**. A key message presented in the introduction of the indicator framework is that all indicators ‘...*should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics....*’. (Goal 17.18).

The global Covid-19 pandemic has worsened inequalities and exposed deep pre-existing discrimination already identified in the SDGs. It is necessary to recognise the disproportionate impacts of Covid-19 and its fallout on persons with disabilities.

We must remember now also the impact of COVID 19 on global development in general, as well as on the most marginalised people, and the important role the EU and the international community will play in the global COVID 19 vaccination roll-out and to stimulate inclusive global recovery.

Ensuring a disability inclusive response to Covid-19

People with disabilities have been, all around the world hit very hard by COVID 19: by the measures taken to control the pandemic, by the pandemic itself- just look at the loss of life for people living in institutional setting in Europe, and by the middle and long term economic consequences.

Our human rights report, documents what happened to people with disabilities during the pandemic, and develops recommendations- both to prevent this happening again, and to ensure that we have an inclusive COVID 19 recovery. Disability inclusive response is an obligation under article 11 CRPD, and the response should also take into account all articles of the CRPD such as right to life (art. 10), accessibility (art. 9), equality and non discrimination (art. 5), gender perspective (art. 6), etc.

EU COVID 19 recovery funding

- The Recovery and Resilience Facility is there to help Ireland and the other Member States set out reforms to recover from the pandemic.

- Following the guidelines given by the European Commission, there should have been extensive consultation with civil society on how and where the funds could be used.
- Ireland's national Recovery and Resilience Plan should focus its ideas for spending on assisting the people in society who were the most affected by the pandemic, and reworking the structures that we saw were insufficient to withstand this health crisis.
- Persons with disabilities should be at the heart of reforms funded by Ireland's Recovery and Resilience Plan. The area of greatest concern is residential care and the tragic number of infections and fatalities we saw there. This EU funding is an opportunity for Ireland to invest more in personalised and community-based support and services to ensure that those requiring care are not left cut off from their communities during times of crisis.
- RRF money needs to focus on impact, but the idea is not to focus on easy target groups that will give quick results. The idea should be to focus first and foremost on the most marginalised groups. For example, assisting persons with disabilities in finding their place in the open labour market, especially after the job loss incurred by the pandemic. Investment should also not shy away from social investments that are more difficult to report on in a quantitative way, such as the social inclusion of marginalised groups.
- Although not governed by the same regulations as other forms of EU investment, it is nevertheless crucial that RRF spending adhere to Ireland's international commitments, such as that to the UN Convention on the Rights of Persons with Disabilities and the EU charter of Fundamental Rights.

Annexed additional information on the topics for discussion:

Examining the need for a standard definition of disability

Article 1 CRPD states that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

In reviewing the implementation of the CRPD, the Committee in Geneva does look at whether the definition(s) of disability used by the State Parties, including in relation to assessment comply with article 1 CRPD- and thus is based on the human rights model of disability. An issue that appeared in many countries is different definitions in different laws and policies, and definition or assessment based on the medical model (e.g. based on the "fitness" or "unfitness" of the person).

For example, the Committee recommended Slovenia to “Conduct a review of its national legislation, policies and programmes and bring them into line with the provisions of the Convention; **including the various definitions of disability in legislation and align it with the human rights model of disability;**”

For example:

Poland ([CRPD/C/POL/C/1](#))

5. The Committee is concerned at the:
- (b) Variety of disability assessment mechanisms, including separate mechanisms for children until 16 years old, as well as the variety of definitions of disability, which are not consistent with the purpose (art. 1) of the Convention, and are all based on a medical-model disability, using derogatory terminology and vague concepts such as “mental retardation”, “incapacity to work”, “inability to perform social roles” or “dependent or lacking ability to be autonomous”;

The Former Yugoslav Republic of Macedonia ([CRPD/C/MKD/CO/1](#))

5. The Committee is concerned about:
- (b) The use of different disability assessments and definitions in the legal framework of the State Party that are not in line with the human rights based model of disability, i.e. in the Law on Prevention of and Protection from Discrimination (LPPD);

Slovenia ([CRPD/C/SVN/CO/1](#))

4. The Committee is concerned about:
- (b) The variety of disability definitions not in compliance with the human rights model of disability, in particular definitions that are derogatory and, point out the ‘unfitness’ of persons to participate in regular education, independent life and work, on the basis of their impairment;
5. The Committee recommends that the State party:
- (a) Conduct a review of its national legislation, policies and programmes and bring them into line with the provisions of the Convention; including the various definitions of disability in legislation and align it with the human rights model of disability;

Safeguarding and confidentiality of data collection and processing

Disability can be considered as sensitive personal data- according to the GDPR definition, sensitive data is **data** consisting of racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, genetic **data**, biometric **data**, **data** concerning health or **data** concerning a natural person's sex life or sexual orientation.

Therefore this disability data can only be processed meeting specific criteria outlined in the GDPR.

the **explicit consent** of the individual was obtained (a law may rule out this option in certain cases);

- an **EU or national law or a collective agreement**, requires your company/organisation to process the data to comply with its obligations and rights, and those of the individuals, in the fields of employment, social security and social protection law;
- the **vital interests** of the person, or of a person physically or legally incapable of giving consent, are at stake
- you are a **foundation, association or other not-for-profit body** with a political, philosophical, religious or trade union aim, processing data about its **members** or about people in regular contact with the organisation;
- the personal data was **manifestly made public** by the individual;
- the data is required for the establishment, exercise or defence of **legal claims**
- the data is processed for reasons of **substantial public interest** on the basis of EU or national law;
- the data is processed for the purposes of **preventive or occupational medicine**, assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment, or the management of health or social care systems and services on the basis of EU or national law, or on the basis of a contract as a health professional;
- the data is processed for reasons of **public interest in the field of public health** on the basis of EU or national law;
- the data is processed for **archiving, scientific or historical research purposes** or statistical purposes on the basis of EU or national law.

COVID 19 recommendations from EDFs human rights report on COVID 19:

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 deprioritisation 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:
 - a. Ensure equality and non-discrimination in legislation and practice for all persons with disabilities.
 - b. Protect persons with disabilities from violence, abuse, exclusion, coercion, and neglect, with disability, gender, and age-sensitive actions.
 - c. Ensure continuous, independent human rights monitoring.
 - d. 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.