

Online regional consultations with persons with disabilities and their representative organizations

For countries in the [European Union, Western European countries and other States](#).

“From isolation, invisibility and segregation into inclusion of persons with disabilities in the community. Identifying and overcoming barriers to the successful process of deinstitutionalization.”

[Committee on the Rights of Persons with Disabilities](#)

Informative note

In 2021, the [Committee on the Rights of Persons with Disabilities](#) (the Committee) is organizing a series of online regional consultations with persons with disabilities, through their representative organizations. This note is about the consultation for countries in the **European Union, other Western European countries, and other States**.

1. What is the Committee on the Rights of Persons with Disabilities?

The Committee is a treaty body of the United Nations. It is established by the Convention on the Rights of Persons with Disabilities. Its task is to monitor how States parties to the Convention implement or give effect to their obligations under this legal instrument. It is comprised of 18 independent experts from all continents of the world, who are elected by the States Parties.

2. What is institutionalization?

For many years, many persons with disabilities have had no choice and control over their lives. People thought persons with disabilities were not able to live independently in a place they choose. They thought that persons with disabilities needed medical treatment in organizations or institutions to correct or cure diseases and physical or intellectual impairments. So countries spent money on special services, isolated from the community, instead of providing support to live in the community. To this day, many persons with disabilities have no choice but to live in institutions, special schools, hospitals, group homes, mental health or psychiatric facilities, residential care facilities, prisons, etc. Many have to live in the family home, or are not allowed to leave the family home even though they are adults and want to live independently. They depend on other persons and have little freedom.

The Convention states that every person with a disability has the right to live independently and be included in the community. All persons with disabilities have this right, whoever they are and wherever they live. It guarantees them freedom, choice and control over the decisions that affect their lives. This right protects the inherent dignity, autonomy and independence of persons with disabilities and secures their full and effective participation and inclusion in society. The Committee wrote a document called [General Comment](#) to explain what [independent living and being included in the community](#) means. The Committee said: "Social

exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalization of persons with disabilities."

3. What is a consultation?

A consultation is a way for persons to share their experiences and ideas on a topic. The topic of this consultation is the right to independent living and being included in the community, recognised in [article 19](#) of the Convention on the Rights of Persons with Disabilities.

4. When is this consultation?

- ✓ The regional consultation will take place on **Tuesday 25 May 2021**, at **10 a.m. Central European Time**.
- ✓ Your country may be in a different time zone. Please check what the local time of the meeting is in the place where you are.

5. Why this consultation?

The COVID-19 pandemic and the measures that countries took to stop the spread put many persons with disabilities at risk of:

- losing their income;
- losing their social protection benefits, such as disability payments and health insurance;
- being forced into institutions;
- being isolated and confined;

The situation may be worse for some groups of persons with disabilities, including:

- those who face multiple discrimination;
- those who are still in institutions;
- persons with intellectual disabilities;
- persons with psychosocial disabilities;
- children;
- older persons;
- women.

6. What is the purpose of this consultation?

The COVID-19 pandemic has made things worse. There are greater inequalities. The consultation is a chance for persons with disabilities to share their experiences and ideas on how to deal with the current situation and the risks persons with disabilities face. In addition, they can express their opinions and ideas on how to change the situation. It is also a chance to share good practices from their region so that persons with disabilities can be included in the community.

The Committee will use the information from the consultation to prepare a document called draft Guidelines on Deinstitutionalization, including in emergencies. The document will provide guidance to countries to put the Convention on the Rights of Persons with Disabilities into practice, especially [the right to living independently and being included in the community \(article 19\)](#), the Committee's [General comment No. 5 \(2017\) on living independently and being included in the community and its Guidelines on liberty and security of the person \(2015\)](#).

7. Who is this consultation for?

- ✓ The Committee wants to hear from persons with disabilities from the countries in the list in [annex 1](#) at the end of this note. We want to hear from:

7.1. Persons with disabilities and organizations of persons with disabilities. This includes organizations of children and young persons with disabilities, self-advocacy organizations, organizations of persons with autism, organizations of persons with intellectual disabilities, organizations of persons with psychosocial disabilities, and organizations of women with disabilities. These speakers have up to 4 minutes each to make their presentations.

7.2. Local, national, regional or international groups of organizations of persons with disabilities (coalition). Every coalition will have up to 6 minutes to make its presentation. Every coalition can request that one speaker or two take the floor making a presentation but they should not go beyond the 6 minutes in total.

7.3. Persons with disabilities participating together with a representative from organizations of parents of persons with disabilities. The two persons may speak for a total of 3 minutes. If an organization of parents cannot encourage persons with disabilities to speak, the organization can participate as an observer.

7.4. Organizations of civil society, national human rights institutions or independent monitoring mechanisms specifically working to end institutionalization or promoting independently living. These speakers will have up to 2 minutes to make a presentations.

7.5. Observers: other interested organizations may observe only but do not deliver an oral speech or presentation.

You can also share your ideas with the Committee in other ways. Please check part Number 11 of this note.

8. How I can register?

8.1 Please send an email to jaraya@ohchr.org Write *Regional consultation European Union, Western Europe, and other States* in the subject of the email.

8.2 In your email, please tell us:

- (a) The full name of the person from your organization that will speak at the consultation;
- (b) The name of your organization;
- (c) The country where the organization is from or where it works.

Attach to the email the statement you want to issue during the consultation. Please only send documents in Word format. Your statement has to be **520 words or less (double-spaced, 12 font)**. Your statements should be **in English**.

8.3 You have to register and send your statements by **12 May 2021**.

8.4 What happens after I register?

- ✓ The consultation is only for persons that register and receive an invitation to speak. Information that is shared during the consultations will be kept confidential. The consultation is only 120 minutes. Please understand that it is difficult to give all persons time to speak. After you register, the Committee will make a list of speakers. To make the list, it will verify if you or your organization:
 - Sent a written statement;
 - Are a person with disabilities or are a member of an organization of persons with disabilities;
 - Work specifically to end institutionalization or promote independent living;
 - The Committee also wants to hear ideas from persons from different countries in the region.

- ✓ We will send you an email to confirm that you will speak during the regional consultation;

- ✓ You will also receive a link to join the Zoom online platform on 25 May 2021;

- ✓ You will receive the list of speakers with the order of speakers.

You can also share your ideas with the Committee in other ways. Please check part Number 11 of this note.

9. What topics will the consultations cover?

Speakers can give ideas about the way forward to put in practice independent living and being part of the community, in a place freely chosen.

9.1 Here are some suggested questions on the topics we would like to cover. These questions can help you to write and make statements in the consultations:

- (a) How are persons with disabilities isolated, marginalized, excluded, segregated or institutionalized in this region? How can these practices end?
- (b) How can we prevent persons with disabilities from being isolated and institutionalized, particularly during the pandemic?
- (c) How can countries make sure that social security systems give individual support to prevent isolation, confinement, marginalization, segregation and institutionalization, especially in emergencies?

(d) How do we make sure that persons with disabilities do not lose their independence with living arrangements, and their control over the use of services and supports, including during emergencies such as the current pandemic?

(e) How can we make sure that persons with disabilities are not forced to go or to return to institutions? These include all places where people with disabilities are isolated such as group homes, special schools, all mental health settings, religious or faith healing settings, and criminal forensic detention.

(f) How should persons with disabilities be supported throughout the deinstitutionalization process to make decisions and to communicate?

(g) How can we end all forms of institutionalization in legislation (laws) and in communities? These include all places where persons with disabilities are isolated such as group homes, special schools, all mental health settings, religious or faith healing settings, and criminal forensic detention.

(h) What needs to happen to eliminate discrimination in law and practice, so everyone can enjoy their right to live independently? How do we make sure that the rights of specific groups are protected from discrimination, isolation, segregation, institutionalization, re-institutionalization, and coercion? Specific groups such as:

- children;
- young persons;
- older persons;
- persons facing multiple forms of discrimination;
- persons requiring high levels of support;
- women with disabilities;
- persons with intellectual disabilities;
- persons with psychosocial disabilities;
- persons with disabilities belonging to indigenous peoples or minority communities.

(i) What support do you and members of the group you represent need now, and in the long-term and in times of crisis support?

(j) What should be available for persons who have been institutionalized to remedy and repair the harms they have suffered? These harms include arbitrary detention, torture, ill or degrading treatment or other forms of coercion in connection with institutionalization.

(k) What are the roles of the different groups such as families, organizations and human rights groups in supporting persons with disabilities when moving from institutions to living independently and being included in the community?

(l) Could you tell us any good practices or experiences from your country or region, in relation to any of these topics or questions?

(m) Could you mention any good practices or experiences to consult and involve persons with disabilities through their representative organizations related to any of the topics or questions mentioned?

10. How will the online regional consultation happen?

The consultation will be online. We will meet through Zoom.

The consultation will last 120 minutes. We will hear from different speakers in the region who will share their experiences and ideas.

Speakers are invited to share ideas on the way forward to end institutionalization, isolation, segregation, and marginalization of persons with disabilities.

Members of the Committee will act as moderators of the consultation. Other members of the Committee will provide a brief evaluation of the consultation.

Each speaker from organizations of persons with disabilities will have 4 minutes to speak.

Speakers who represent local, national, regional or international groups of organizations of persons with disabilities (coalition) will have up to 6 minutes.

Persons with disabilities participating together with a representative from organizations of parents of persons with disabilities will have 3 minutes total.

If there is enough time, organizations of civil society, national human rights institutions or independent monitoring mechanisms specifically working to end institutionalization or promoting independent living will have 2 minutes.

The consultation will be in English.

- ✓ Please activate the “Captioning” function in Zoom for captioning in English.
- ✓ International Sign will be provided.

11. Are there other ways to give information to the Committee:

If you cannot participate online, you can send information about **one or more of the topics and questions in subheading Number 9.1 of this note** in the following ways:

You can use [WeTransfer](#) to send to jaraya@ohchr.org either:

- (a) A written statement. The statement should be 520 words or less (double-spaced, 12 font); or
- (b) A video message of up to 4 minutes; or
- (c) A voice recording of up to 4 minutes.

* This informative note has been prepared by the Committee's Working Group on Deinstitutionalization. The [International Disability Alliance](#), the European Network for Independent Living, Inclusion International, Validity Foundation and other civil society organizations also contributed.

ANNEX 1 List of countries:

Andorra
Austria
Belgium
Bulgaria
Croatia
Cyprus
Czech Republic
Denmark
Estonia
Finland
France
Germany
Greece
Hungary
Iceland
Ireland
Israel
Italy
Latvia
Liechtenstein
Lithuania
Luxembourg
Malta
Monaco
Netherlands
Norway
Poland
Portugal
Romania
San Marino
Slovenia
Slovakia
Spain
Sweden
Switzerland
Turkey
United Kingdom of Great Britain and Northern Ireland
