## Online regional consultations with people with disabilities and their representative organizations **in the Caribbean and North America**:

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

#### [Committee on the Rights of Persons with Disabilities](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx)

#### Informative note for stakeholders

In 2021, the members of the [Committee on the Rights of Persons with Disabilities](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx) (the Committee) are organizing a series of online regional consultations with people with disabilities, through their representative organizations. This note is about the consultation for countries in the Caribbean and North America.

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

The Committee on the Rights of Persons with Disabilities is a treaty body of the United Nations. It is established by the [Convention on the Rights of Persons with Disabilities](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx) (The Convention). It is a group of 18 experts from different countries and all continents of the world, whose task is to monitor or check how the Convention on the Rights of Persons with Disabilities is being used in countries.

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 isolated in family home, in institutions, special schools, 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. The Committee wrote a document called General Comment No. 5 to explain what i[ndependent living and being included in the community](file:///C:/Users/fuentes/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/YI4CFVN8/General%20comment%20No.%205%20(2017)%20on%20living%20independently%20and%20being%20included%20in%20the%20community%20and%20its%20Guidelines%20on%20liberty%20and%20security%20of%20the%20person%20(2015)) 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 people 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](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19) of the Convention.

4. When is this consultation?

* The regional consultation for the Caribbean and North America will take place on **Tuesday 8 June 2021, at 10h00 a.m. (Kingston, Jamaica time).**
* Your country may be in a different time zone. Please check what the time of the meeting is in the local time where you are: <https://www.timeanddate.com/worldclock/converter.html>

5. Why this consultation?

5.1 The COVID-19 pandemic and the measures that countries took to stop the spread put many people 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.

5.2 The situation is worse for some groups of people with disabilities, including:

- those who face multiple discrimination;

-those who are still in institutions;

-people with intellectual disabilities;

- people with psychosocial disabilities;

-children;

-older people;

-women and girls with disabilities.

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 people with disabilities to share their opinions and ideas on how to change the situation. People with disabilities can share their experiences and ideas on how to change the current situation and eliminate the risks people with disabilities face. It is also a chance to share good practices from their region so that people 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 have suggestions for 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)](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19), the Committee’s [General comment No. 5 (2017) on living independently and being included in the community](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en) and its [Guidelines on liberty and security of the person (2015)](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=A/72/55&Lang=en).

7. Who is this consultation for?

* The Committee wants to hear from people with disabilities from the countries in the list in [**annex 1**](#Annex1) at the end of this note. We want to hear from:

7.1. People with disabilities and organizations of people with disabilities. This includes organizations of children and young people with disabilities, self-advocacy organizations, organizations of autistic people, organizations of people with intellectual disabilities, organizations of people 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 people with disabilities (coalition). Every coalition will have up to 6 minutes to make its presentation.

7.3. People with disabilities participating with a representative from parents’ organizations. The two people may speak for a total of 3 minutes. If an organization of parents cannot encourage people 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.

8. How I can register?

8.1 Please send an email to [jaraya@ohchr.org](mailto:jaraya@ohchr.org) Write *Regional consultation Caribbean and North America* in the subject of the email.

8.2 In your email, please tell us:

1. The full name of the person from your organization that will speak at the consultation;
2. The name of your organization;
3. The country where the organization is from or where it works.

**Please attach to the email the statement you want to say** 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 Please register and send your statement by Tuesday **25 May 2021**.

8.4 What happens after I register?

* The consultation is only for people that register and receive an invitation to speak. Information that is shared during the consultations will be kept confidential. After you register, the Committee will make a list of speakers. To make the list, it will check if you or your organization:
* Sent a written statement;
* Are a person with disabilities or are a member of an organization of people with disabilities;
* Work specifically to end institutionalization or promote independent living;
* The Committee also wants to hear ideas from people from different countries in the Caribbean and North America.
* 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 **8 June 2021**;

9. What topics will the consultations cover?

9.1 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. Here are some suggested questions on the topics we would like to cover.

(a) How are people with disabilities isolated, marginalized, excluded, segregated or institutionalized in the Caribbean and in North America regions? How can these practices end?

(b) How can we prevent people 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, marginalization, segregation and institutionalization, especially in emergencies?

(d) How do we make sure that people 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 people 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, colonies for persons affected by leprosy, all mental health settings, religious or faith healing settings, and criminal forensic detention.

(f) How should people 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 (like laws) and in communities? This include all places where people with disabilities are isolated such as group homes, special schools, colonies for persons affected by leprosy, 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, confinement, segregation, institutionalization, re-institutionalization, and coercion? Specific groups such as:

children;

young persons;

older persons;

people requiring high levels of support;

women with disabilities;

people with intellectual disabilities;

people with psychosocial disabilities;

people with disabilities belonging to indigenous or minority communities.

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

(j) What should be available for persons who have been institutionalized to remedy, or 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 people with disabilities when moving from institutions into 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 people 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 people with disabilities.

10. 1 Speakers during the consultation will have different time slots:

* Persons with disabilities and speakers from organizations of people with disabilities will have 4 minutes to speak.
* Speakers who represent local, national, regional or international groups of organizations of people with disabilities (coalition) will have up to 6 minutes. 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.
* People with disabilities participating together with a representative from organizations of parents of people with disabilities will have 3 minutes total.
* Organizations of civil society, national human rights institutions or independent monitoring mechanisms specifically working to end institutionalization or promoting independently living will have 2 minutes, if time allows it.

10.2. The consultation will be in English.

* Please activate the Captioning function in Zoom for captioning in English.
* International Sign will be provided.
* Translation into English 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](https://wetransfer.com/) to send to [jaraya@ohchr.org](mailto: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 minute

\* 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 in the Caribbean and North America**:

Antigua and Barbuda

Bahamas

Barbados

Belize

Canada

Dominica

Guyana

Grenada

Haiti

Jamaica

Saint Kitts and Nevis

Saint Lucia

Saint Vincent and the Grenadines

Surinam

Trinidad and Tobago

United States of America