

African Disability Forum, Arab Organization of Persons with Disabilities, ASEAN Disability Forum, Down Syndrome International, European Disability Forum, Inclusion International, International Federation of Hard of Hearing People, International Federation for Spina Bifida and Hydrocephalus, Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families, Pacific Disability Forum, World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind, World Network of Users and Survivors of Psychiatry

# Submission on draft general recommendation no. 37 (2023) on racial discrimination in the enjoyment of the right to health

# By the International Disability Alliance

# August 2023

## INTRODUCTION

1. The International Disability Alliance (IDA) is a unique, international network of eight global and six regional organizations of persons with disabilities (OPDs). Each IDA member represents a large number of national OPDs, covering the whole range of disability constituencies. IDA thus represents the collective global voice of persons with disabilities counting among the more than 1 billion persons with disabilities worldwide, the world’s largest –and most frequently overlooked– minority group.
2. IDA thanks the Committee on the Elimination of Racial Discrimination (hereinafter “the CERD Committee”) and welcomes this opportunity to provide comments to the Draft General Recommendation No. 37 (2023) on racial discrimination in the enjoyment of the right to health (hereinafter “the draft”).
3. IDA welcomes several references to persons with disabilities, disability, and issues related to persons with disabilities throughout the draft. This submission addresses key sections of the draft seeking to contribute to its improvement in terms of mainstreaming the rights of persons with disabilities for the CERD Committee to provide better guidance to States Parties to the Convention on the Elimination of All Forms of Racial Discrimination. It also complements [our submission](https://www.ohchr.org/en/events/days-general-discussion-dgd/2022/thematic-discussion-racial-discrimination-and-right-health) for the Day of General Discussion held in August 2022 and provides concrete drafting suggestions for the text of the draft.

## INTERSECTIONALITY AND NON-DISCRIMINATION

1. IDA welcomes paragraph 9 of the draft which recognizes intersectionality as a guiding principle. The draft further defines intersectional discrimination which explicitly recognizes disability as one of the intersectional grounds. IDA further welcomes para 38which encourages States to explicitly refer to intersectionality recognizing the prohibition of racial discrimination, as defined in Article 1(1) of the Convention, intersecting with other grounds of discrimination, including disability.
2. Broadening and strengthening anti-discrimination laws and human rights frameworks has led to extended protection of the rights of persons with disabilities. IDA is concerned that while disability has explicitly been included as an intersectional ground, disability-based discrimination has not been discussed. IDA believes that the draft would benefit from explicitly referring to disability-based discrimination and related concepts to better address intersectional discrimination based on race and disability equipped with a clear understanding of disability and CRPD standards.
3. The CRPD defines discrimination as “any distinction, exclusion, or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It also **includes all forms of discrimination, including denial of reasonable accommodation**.”[[1]](#footnote-1) Denial of reasonable accommodation constitutes discrimination if the necessary and appropriate modification and adjustments needed to ensure the equal enjoyment or exercise of a human right or fundamental freedom (that do not impose a “disproportionate or undue burden”) are denied.[[2]](#footnote-2) In the case of persons with disabilities, intersectional discrimination occurs when a person with disability or associated to disability suffers discrimination of any form on the basis of disability, combined with, colour, sex, language, religion, ethnic, gender or other status. It can also be direct or indirect discrimination, denial of reasonable accommodation or harassment.[[3]](#footnote-3)
4. In the context of health, the Committee on Economic and Social Cultural Rights (CESCR Committee) reminds State's substantive equality requires the specific needs of particular groups including persons with disabilities to be addressed.[[4]](#footnote-4) To this end and in the context of sexual and reproductive health and rights, General Comment No.22 obligates States to provide reasonable accommodation to enable persons with disabilities to fully access sexual and reproductive health services on an equal basis.[[5]](#footnote-5)
5. It would be useful for the General Recommendation to explore root causes and the nature of intersecting discrimination, which are often due to racial, gender, ableist and other stereotypes. For example, in the context of mental health, African American men with psychosocial disabilities are stereotyped as considered dangerous because of their race (African American), their gender (male), and even more dangerous because they have an actual or perceived psychosocial disability. African American women with disabilities face discrimination in relation to their sexual and reproductive health and rights, because of intersecting racial, sexual, and ableist stereotypes suggesting that they are hypersexual and not fit to be mothers. These stereotypes often result in significant racial discrimination and violation of other rights including by forced treatment, or inadequate or inappropriate medical service provision.[[6]](#footnote-6)
6. We note recent WHO reporting on the intersection of race and disability affecting health equity[[7]](#footnote-7), highlighting the following:
	1. In the United States, persons with intellectual or developmental disabilities from Black and Latino populations are more likely to be uninsured medically compared to white persons with intellectual and developmental disabilities, compromising their access to health services and the quality of care they receive.
	2. There are higher rates of institutionalization and forced treatment in mental health in the UK among those who are from Black African and Black Caribbean ethnic origins (something highlighted in CERD’s review of the UK, see paragraph 20 of this submission)
	3. Indigenous peoples with disabilities often experience multiple discrimination and face barriers to the full enjoyment of their health, based on their indigenous status and on disability.
7. IDA proposes broadening the definition of intersectional discrimination in paragraph 9 to **explicitly include denial of reasonable accommodation:**

 “Intersectional discrimination, on grounds of race, colour, descent, national or ethnic origin operating and interacting at the same time with any other ground, such as gender, age, disability, migratory status, class, social status, or income, in such a way that they are inseparable, is a form of racial discrimination which must be eliminated **and racial, gender, ableist and other stereotypes combatted and eradicated. For the case of persons with disabilities, discrimination shall include denial of reasonable accommodation**.”

## THE RIGHT TO LEGAL CAPACITY (ARTICLE 12 OF THE CRPD)

1. IDA welcomes **paragraph 21** of the draft general recommendation which highlights the denial of legal capacity and its impact on the right to provide consent. As highlighted in the [previous submission](https://www.ohchr.org/en/events/days-general-discussion-dgd/2022/thematic-discussion-racial-discrimination-and-right-health), legal capacity is indispensable for the exercise of rights including the right to health. Indeed, the CRPD Committee has stressed this correlation stating that **“legal capacity acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health.”**[[8]](#footnote-8).
2. However, denial of legal capacity remains pervasive in many jurisdictions. Substituted decision-making and lack of supported decision-making result in persons with disabilities being subjected to egregious practices such as forced treatment, forced sterilization, forced contraception, forced abortion, and institutionalization.[[9]](#footnote-9)
3. IDA is concerned that by connecting the issue of deprivation of legal capacity only to the practice of forced sterilization in paragraph 21, States would miss the general relevance of the exercise of legal capacity in line with the CRPD for all health-related decisions.
4. IDA proposes that paragraph 17 is amended as follows:

“Article 5 (e)(iv) requires States to respect, protect and fulfil the freedom from racial discrimination in the right to control one’s health and body, including sexual and reproductive freedom, and the freedom from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. **Guaranteeing the right to legal capacity for all including persons with disabilities, not allowing third parties such as guardians, to give consent on their behalf, is essential the enjoyment of these fundamental rights”.**

## ABSOLUTE BAN ON DEPRIVATION OF LIBERTY ON THE BASIS OF IMPAIRMENT

1. IDA welcomes paragraph 19 which links deprivation of liberty “to disproportionate restrictions in the right to control one's health and bodies and be free from non-consensual medical treatment, including as a preventative measure to address the impact of imprisonment on mental health.”
2. However, IDA is concerned that the draft does not explicitly contextualize the intersectional discrimination that persons with psychosocial disabilities face with regard to deprivation of liberty owing to the actual or perceived impairment.[[10]](#footnote-10) The CERD Committee also misses an opportunity to explicitly include mental health institutions as places where racial minorities are overrepresented. As highlighted in paragraph 9 of [our previous submission](https://www.ohchr.org/en/events/days-general-discussion-dgd/2022/thematic-discussion-racial-discrimination-and-right-health), persons with actual or perceived psychosocial disabilities and/or persons with mental health conditions from racial minorities are overrepresented among those institutionalized in inpatient care, contrary to the right to liberty under the CRPD, where they face stigmatization, risk of ill-treatment and torture among others.
3. Indeed, the CERD Committee during its dialogue with United Kingdom of Great Britain and Northern Ireland, was particularly concerned about “reports of overrepresentation of persons of Afro-Caribbean descent in psychiatric institutions and of a higher likelihood of persons of Afro-Caribbean descent being subjected to restraint, seclusion and overmedication.” [[11]](#footnote-11)
4. Article 14 of the CRPD recognizes the right to liberty and security of persons with disabilities. As a measure to guarantee this right, the CRPD Committee has called for an absolute ban on deprivation of liberty on the basis of disability whether considered alone or in conjunction with other grounds such as “care”, “treatment” or “dangerousness”.[[12]](#footnote-12) IDA believes that the CERD Committee will benefit from the CRPD standards by explicitly calling for an absolute ban on the deprivation of liberty of racial minorities based on their impairment.
5. Based on the above, IDA proposes the following amendments:
	1. To paragraph 19, explicitly refering to overrepresentation in “psychiatric institutions” as follows: “Deprivation of liberty, due to over policing, racial profiling, and overrepresentation in the penitentiary system and psychiatric institutions leads to disproportionate restrictions …
	2. To paragraph 38 as follows, “The scope of the prohibition of racial discrimination should include both the right to a system of health protection and the right to control one’s individual health and body, as well as the freedom from torture, non-consensual medical treatment, and experimentation, while any reference to Article 12 ICESCR and **Article 14 CRPD,** as interpreted by the CESCR and **CRPD Committee respectively**, would enhance harmonization across the UN treaty system.”

## SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

1. IDA welcomes paragraph 20 which recognizes racial discrimination in the context of sexual and reproductive health and recalls that intersecting with other forms of discrimination, including disability, it might result in violation of sexual and reproductive health and rights.
2. IDA further welcomes the recognition in paragraph 21 that reproductive violence, in particular forced sterilization, disproportionately affects women with disabilities owing to pervasive practices that deny them the right to make decisions about their bodies. The CRPD Committee further recognizes that “in addition to facing barriers resulting from multiple discrimination on the grounds of gender and disability, some women with disabilities, such as refugees, migrants, and asylum seekers, face additional barriers because they are denied access to health care.”[[13]](#footnote-13)
3. The CRPD Committee has urged States to end harmful practices including forced contraception, forced abortion, and forced sterilizations.[[14]](#footnote-14) Its General Comment no. 3 recognizes that “restricting or removing legal capacity can facilitate forced interventions including such as sterilization, abortion, and contraception.”[[15]](#footnote-15) The existence of substituted decision-making coupled with harmful stereotypes and false beliefs means women with disabilities could be forced into receiving an unwanted abortion or forcibly subjected to contraception or family planning as a “precautionary” measure to prevent pregnancy, a practice derived from disability stigma.[[16]](#footnote-16)
4. While welcoming the recognition that “women with mental illnesses” are more likely to be subjected to reproductive violence compared to others, IDA is concerned about the term “women with mental illnesses,” based on the outdated medical model of disability. The CRPD Committee utilizes the term “persons with psychosocial disabilities” which is free from that outdated approach and is consistent with the concept and human rights model of disability.
5. The emphasis on “women with psychosocial disabilities” might overlook women with intellectual disabilities who face similar intersectional discrimination based on their impairment. The CRPD Committee has highlighted that “persons with cognitive disabilities and psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity,”[[17]](#footnote-17) and consequently, highly exposed to reproductive violence, including forced abortion, forced sterilization, and forced contraception.[[18]](#footnote-18)
6. In light of the above, IDA proposes the following amendments:
	1. To paragraph 21:

Title: “*(i) Forced sterilizations****, forced contraception and forced abortions***”

To the text: “The Committee recognized that some forms of racial discrimination, such as coerced or forced sterilization, may be specifically directed towards women due to their gender. Indigenous, women of African descent, Roma and women belonging to other ethnic groups and castes, including women **~~suffering from mental health illness~~ psychosocial disabilities and intellectual disabilities** within these groups, have been disproportionately targeted in policies related to population control or control of infectious diseases, such as HIV/AIDS, including coercive sterilizations, **forced contraception and forced abortions.”**

## PARTICIPATION OF PERSONS WITH DISABILITIES THROUGH THEIR REPRESENTATIVE ORGANIZATIONS IN POLICY-MAKING AND MONITORING

1. IDA welcomes paragraph 29 of the draft which highlights participation, consultation, and empowerment as general obligations for ending racial discrimination. The draft recognizes the need for a broader engagement of stakeholders including community organizations and civil society organizations.
2. The CRPD has made a great contribution to international human rights law in this area. Article 4(3) of the CRPD provides: “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”
3. . The obligation to include organizations of persons with disabilities is further enshrined in article 33(2) and (3) which require States to establish a national independent monitoring mechanism and involve civil society, including organizations of persons with disabilities, in monitoring activities, respectively. CRPD Committee’s general comment no. 7 elaborates further on Article 4(3) and Article 33(3) CRPD. It requires States to “systematically and openly approach, consult and involve, in a meaningful and timely manner, organizations of persons with disabilities”.[[19]](#footnote-19)
4. In relation to the right to health, the CRPD Committee has stressed the necessity “to implement monitoring and review mechanisms in relation to persons with disabilities deprived of their liberty”.[[20]](#footnote-20) Article 16(3) of the CRPD explicitly requires monitoring of all facilities and programmes that serve persons with disabilities in order to prevent all forms of exploitation, violence, and abuse.
5. Specifically on inclusion and participation of groups within the purview of the Convention including persons with disabilities from cultural and linguistic minorities, the CRPD Committee recommended Australia to involve “Aboriginal and Torres Strait Islander persons with disabilities and their representative organizations in particular in all aspects of the design, implementation, monitoring and evaluation of the Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability”.[[21]](#footnote-21) In this same direction, the draft recognizes that “[p]articipation and consultation of groups within the purview of the Convention in health decision-making integrates their knowledge and improves the quality of the decisions, promotes legitimacy and transparency among others.”
6. Participation can be either direct (individual) or indirect through representative organizations (groups).[[22]](#footnote-22) The draft can be clearer in including both cases, acknowledging the role of representative organizations of persons with disabilities, as foreseen in article 4(3) of the CRPD, as well as on the need to give priority to their views in matters that concern persons with disabilities over the views of organizations *for* persons with disabilities and service providers.[[23]](#footnote-23)
7. IDA welcomes the specific references on participation and, with a view to reinforcing them, proposes to amend the last sentence of paragraph 29 as follows:
	1. To paragraph 29: “If communities within the purview of the Convention are **actively consulted and effectively involved** in the decision-making, at community, local, regional, or national level, they exercise their right to be heard and their right to information.”
	2. To paragraph 30: “States must guarantee that access to information and the right to participation is provided to persons protected under the Convention as individuals and **through their representative organizations. In matters that concern their rights, the views of persons with disabilities and their organizations should be given priority over the views of organizations *for* persons with disabilities and service providers** […]”.

## DATA DISAGGREGATION & MONITORING INDICATORS

1. IDA welcomes paragraphs 44 to 47 of the draft, which stresses the need for States to collect disaggregated data including by disability. Accurate and comprehensive data collection and analysis is a prerequisite for designing, implementing, and monitoring disability-inclusive policies and programs and be equipped to address intersectional inequalities and discrimination based on race and disability.
2. The draft recommends generally that disaggregated quantitative and qualitative data be based on demographic and health indicators. Such a reference remains very broad and might not assist States in utilizing available tools to improve data disaggregation by disability and be able to tackle intersectional inequalities and discrimination.
3. The Washington Group on Disability Statistics has developed an appropriate set of questions for national census and surveys,[[24]](#footnote-24) which has been utilized already in over 80 countries to measure disability prevalence.[[25]](#footnote-25) The CRPD committee has consistently urged States to use the Washington Group of Short set of questions due to its effectiveness in documenting accurate data on persons with disabilities in surveys and national census.[[26]](#footnote-26)
4. For the purpose of monitoring compliance with human rights of persons with disabilities, the Office of the High Commissioner for Human Rights (OHCHR) has developed illustrative human rights indicators on the CRPD to “give guidance on actions and measures to be taken in implementing the CRPD and facilitating assessment of this progress”.[[27]](#footnote-27) For instance, Article 25 of the CRPD on the right to health has several indicators which can be utilized to monitor racial discrimination in health including indicator 25.25 on the “Probability of dying (per 1000) between ages 15 and 60 years, disaggregated by sex (WHO indicator), **disability**, and **indigenous/minority background**”.
5. To this end, **IDA proposes that explicit references to the Washington Group on Disability Statistics and its tools and to OHCHR illustrative human rights indicators on the CRPD** are included in paragraphs 44 and 45, respectively, providing more concrete elements to States Parties to consider in these areas.
1. Article, 2, CRPD. [↑](#footnote-ref-1)
2. CRPD/C/GC/6, para. 18 (c). [↑](#footnote-ref-2)
3. CRPD/C/GC/6, para. 19. [↑](#footnote-ref-3)
4. E/C/12/GC/22, para. 24. [↑](#footnote-ref-4)
5. E/C/12/GC/22, para. 22. [↑](#footnote-ref-5)
6. See e.g. SR on Health’s report on Racism and Health, para. <https://www.undocs.org/A/77/197> ; SR Disabilities report on SRHR <https://undocs.org/en/A/72/133>; SR Disabilities report on deprivation of liberty https://undocs.org/en/A/HRC/40/54 ; SR Disabilities report on impact of ableism in medical and scientific practice; OHCHR report on Article 8 of the CRPD https://www.undocs.org/en/A/HRC/43/27 [↑](#footnote-ref-6)
7. WHO Global Report on Health equity for persons with disabilities, page 86, https://www.who.int/publications/i/item/9789240063600 [↑](#footnote-ref-7)
8. CRPD/C/GC/1, para. 8. [↑](#footnote-ref-8)
9. See CRPD Committee concluding observations on Articles 12, 14, and 17 available at <<https://www.internationaldisabilityalliance.org/content/ida%E2%80%99s-compilations-crpd-committee%E2%80%99s-concluding-observations>> [↑](#footnote-ref-9)
10. See CRPD Committee, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities, paras. 6, 10, 13 (2015) [↑](#footnote-ref-10)
11. CERD/C/GBR/CO/21-23, para. 30. [↑](#footnote-ref-11)
12. CRPD Committee, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities, paras. 7 and 8 (2015); Guidelines on Article 14 of the CRPD. [↑](#footnote-ref-12)
13. CRPD/C/GC/3, para. 39. [↑](#footnote-ref-13)
14. CRPD/C/LAO/CO/1, para. 30; CRPD/C/BGD/CO/1, para 35; CRPD/C/VEN/CO/1, para 32; CRPD/C/IND/CO/1, para. 36 (1). [↑](#footnote-ref-14)
15. CRPD/C/GC/3, para. 34. [↑](#footnote-ref-15)
16. Access, Autonomy, and Dignity: Abortion Care for People with Disabilities, available at < https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-abortion.pdf> [↑](#footnote-ref-16)
17. CRPD/C/GC/1, para 9. [↑](#footnote-ref-17)
18. See concluding observations on Articles 16 and 17 available at <https://www.internationaldisabilityalliance.org/content/ida%E2%80%99s-compilations-crpd-committee%E2%80%99s-concluding-observations> [↑](#footnote-ref-18)
19. CRPD/C/GC/7, para. 22. [↑](#footnote-ref-19)
20. Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities. [↑](#footnote-ref-20)
21. CRPD/C/AUS/CO/2-3, para. 8. [↑](#footnote-ref-21)
22. A/HRC/31/62, para. 23. [↑](#footnote-ref-22)
23. See, CRPD Committee, general comment no. 7 on articles 4(3) and 33(3) CRPD, paras. 13-14. [↑](#footnote-ref-23)
24. More details available here <<https://www.washingtongroup-disability.com/>> [↑](#footnote-ref-24)
25. See at Washington Group on Disability Statistics ‘An Introduction to the Washington Group on Disability Statistics Question Sets’ <https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/An\_Introduction\_to\_the\_WG\_Questions\_Sets\_\_2\_June\_2020\_.pdf> [↑](#footnote-ref-25)
26. See concluding observations in relation to Article 31 available at <<https://www.internationaldisabilityalliance.org/content/ida%E2%80%99s-compilations-crpd-committee%E2%80%99s-concluding-observations>> [↑](#footnote-ref-26)
27. More details available here < <https://www.ohchr.org/en/disabilities/human-rights-indicators-convention-rights-persons-disabilities-support-disability-inclusive-2030#:~:text=In%20the%20framework%20of%20the,implementation%20of%20the%20Convention's%20provisions.>> [↑](#footnote-ref-27)