## **REGIONAL CONSULTATIONS**

## “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](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx)

**Summary note regional consultation**

**of AFRICA**

1. **ORGANIZATIONAL MATTERS**
2. Logistics and organizational matters. The consultation took place online and the programme included four sub-regional groups: Central Africa, Western Africa, Eastern Africa and Southern Africa. Mr. Danlami Basharu member of the Committee was the main moderator, Ms. Gertrude Fefoame was the alternate moderator. The language of the meeting was English and interpretation into French and Portuguese were available. International Sign and Captioning were provided.
3. Participants in the regional consultations. The consultation reached 170 participants, of whom 34 were accredited as speakers. All members of the Committee that come from Africa joined the Consultation: Ms. Gertrude Fefoame, Ms. Soumia Amrani, and Mr. Samuel Kabue. The Vice-Chairs of the Committee Ms. Amalia Gamio and Mr. Jonas Ruskus also joined as well as Ms. Odelia Fitoussi, Rapporteur of the Committee and Mr. Robert Martin, co-chair of the Working group on Deinstitutionalization.
4. Persons with disabilities, organizations of persons with disabilities, coalitions of persons with disabilities, and other civil society organizations and stakeholders intervened delivering testimonies and recommendations about the topics subject to the consultation. Persons with disabilities who have experienced institutionalization delivered individual testimonies, some of them supported by personal assistants or interpreters. Several observers attended the consultation, including persons with disabilities, organizations of persons with disabilities, and national human rights institutions. The Committee received 63 written statements.
5. Groups of persons with disabilities taking part in the consultation included: persons with intellectual disabilities, persons with psychosocial disabilities, persons with visual impairments, persons with deafblindness, persons with hearing impairments, women and girls with disabilities, children with disabilities, persons with autism, persons with albinism, family members of persons with disabilities.
6. Through the online consultations and the written submissions, persons with disabilities from the following countries were represented: Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Chad, Comoros, Congo, Djibouti, Equatorial Guinea, Eritrea, Eswatini, Ethiopia, Gabon, Ghana, Guinea, Guinea-Bissau, Ivory Coast, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, South Sudan, Sudan, Tanzania, the Central African Republic, the Democratic Republic of Congo, The Gambia, Togo, Tomé and Principe, Uganda, Zambia and Zimbabwe.
7. **CONCERNS AND RECOMMENDATIONS OF ACTION**

The following is a summary of concerns and recommendations raised by participants to be considered throughout the drafting of the Committee’s Guidelines on deinstitutionalization. To facilitate the reading, concerns and recommendations are grouped under headings related to the provisions of the Convention.

***De facto discrimination on the basis of disability, and discrimination in legislation and policies***

***Concerns:***

* *Society has been used to the welfare approach to issues concerning persons with disabilities as opposed to a rights-based approach, which includes active promotion of their rights;*
* *“Medical-modelled prevailing laws and policies” has led to and continues to lead to isolation, exclusion, segregation or institutionalization of persons with disabilities;*
* *Persons with disabilities are being looked down upon as low-class citizens;*

***Recommendations:***

* *Ensure that young people are adequately prepared before exit from institutions psychologically and emotionally because although the environment in the institution is not the best, they have formed attachments, it is often the only familiar environment they know;*

***Legislation, including implementation (art.4)***

***Concerns:***

* *In many African countries there is a lack internal legislation referred to the right of living independently;*
* *The lack of political will towards issues related to disability inclusion has hindered the desired progress needed to affect positive substantial change for people with disabilities;*

***Public policies, including deinstitutionalization (art.4)***

***Concerns:***

* *Unfairness in policy making systems and strategies, in most cases persons with disabilities are subjected to the same conditions or demands with those who are able but left out in the law-making systems;*
* *Returnees from institutions have raised concerns including: poor security, difficult access to basic needs especially food, shelter, and extreme financial difficulty because of unpreparedness of their relatives to have them back;*
* *People with little or no experience of disability or providing support for persons with disabilities making policies for persons with disabilities misalignment.*

***Recommendations:***

* *Policy makers should rethink some of the strategies of deinstitutionalization and realise that there is more to treating and managing mental health issues than institutions and medication.*
* *The success of the community-based service scheme would also depend on auditing and monetary based plans. Convening a task force of legislators, state agencies, providers and persons with disabilities and their families to discuss and report on the service needs of people with disabilities is critical process;*
* *Support the construction of Community-based care centres;*

***Funding (art.4)***

 ***Recommendations:***

* *The associations working for people with autism, intellectual and psychosocial disabilities as well as their families have rarely received financial support from the government or UN Bodies;*
* *Extend funding and resources to lived experience organisations to enable them to actively take part in improving the status quo and human rights framework;*
* *The governments should see that there is always a grant to support all persons with disabilities and not only the ones affected by the so called “severe impairments” to give persons with disabilities a sense of belonging.*

***Participation of persons with disabilities (art.4 (3))***

***Recommendations:***

* *Ensure the participation of persons with disabilities in governance processes from local government to national level;*
* *The governments should organize panels or advocacy group of legislators, state agencies, providers and persons with disabilities and their families to discuss and report on the service needs of people with disabilities;*
* *Develop intervention that promote “Social Role Valorisation”;*

***Different pathways to and root causes of institutionalization:***

***Concerns:***

* *Disability stereotypes and their impact: misconceptions about causes of disability from the cultural perspectives, such as traditional religious beliefs, curses, taboos, myths and its resulting impact causing stigma, negative attitudes and high-level of discrimination;*
* *It has been reported that families intentionally lock up persons with disabilities in their houses during public events to prevent stigmatization of their members.*
* *Persons with disabilities face stigma, discrimination and widespread exclusion from mainstream socio-economic activities;*
* *It has been reported that Tribe Chiefs by custom are not permitted to have a physical interaction with any person with disabilities at any public gathering;*
* *Persons with disabilities are often even treated as objects of pity, their segregated institutions become photo-opportunities for businesses and their corporate social responsibility programs/activities;*
* *Families tend to look out for any form of disabilities to qualify or disqualify members from contracting marriages;*
* *Stigma and discrimination rob persons with disabilities of their human dignity and respect in society.*
* *Persons with psychosocial disabilities have been denied status within the legal system as such they are almost never recognized as a subject before the law and further deprived of legal agency which is the ability to act within the legal system.*

***Recommendations:***

* *Explore the pursuit of equality, the principles of non-discrimination and reasonable accommodation adopting a human rights model to psychosocial disabilities, a paradigm shift from the medical model.*

***Situations of poverty, lack of financial support to families of children with disabilities, and situations of deprivation leading to exclusion of persons with disabilities and institutionalization (arts. 5, 19, 28)***

***Concerns:***

* *Persons with disabilities have little or no means of earning incomes, they are let alone in a state of poverty induced by capitalist systems that tend to overlook their interests and needs;*
* *Many families of children with disabilities are in distress as they care for children whom they are not ready to bond with due to the stigma and discrimination;*
* *At family level the expenses of mental health services increases a financial load on the family. The family meets all the “care needs” of the person in most cases for all their lives. The economic situation brigs the families of persons with disabilities to consider sending their members with disabilities to institutions;*

***Women with disabilities (art.6)***

***Concerns:***

* *Women and girls with disabilities faced an increased risk of rape and other forms of sexual violence, often with impunity, due to perceptions they're disabilities where a burden to the family or that such persons were of less value and could be abused;*
* *Teenage pregnancy among girls with disabilities is alarming, poverty is one major course as culture and superstition, ignorance, defilement;*

***Recommendations:***

* *Ensure personal assistance, home care and rehabilitation services, where appropriate, which must be continuous to ensure the exercise of the rights of women and girls with disabilities, considering the importance of community support;*
* *Ensure that women and girls with disabilities, through their representative organizations, are consulted and involved in a continuous and active manner in the planning, implementation and monitoring policies regarding persons with disabilities;*
* *Ensure the protection of women and girls with disabilities from all forms of violence, abuse or mistreatment, using precautionary measures to remove the abuser from their home or residence if this is not possible, women and girls with disabilities should be transferred to safe and free places that protect their personal well-being, which must be fully accessible.*

***Children with disabilities (art.7)***

***Concerns:***

* *Children with disabilities are no exception as they continue to face abuses in state-care as well as barrier to education that often led to segregation in a special school or isolation at home;*
* *Most children and young persons with disabilities, especially those with a higher requirements of support, remain in isolated homes, others bedridden or chained, accentuating their limitations;*
* *Children and young people with disabilities in orphanages are often convinced that the only way to be part of the society is to experience life through other people;*
* *The level of stigma is high especially for children who are vulnerable to emotional discrimination and stigma many complaints indicate that especially people with albinism are still considered as second citizens;*
* *Children living with albinism living with disadvantaged background live in fear that someone is in search for their body parts, highly demanded due to traditional beliefs.*

***Recommendations:***

* *All children living with albinism should be protected by the state as all the other children following the principle of equity than equality if we want to all grow in the same standard;*
* *The society should stop seeing children with disabilities as community projects and look at them as human beings.*

***Awareness Rising (art.8)***

***Recommendations:***

* *Support sensitization and awareness campaigns in the communities to stop discrimination against persons with disabilities, calling for their inclusion and independence.*

***Effect of the Covid-19 Pandemic or other emergencies (art.10-11)***

***Concerns:***

* *The health guidelines or rules for COVID-19 prevention measures are not favorable to persons with disabilities, for instance:*

*a) Washing of hands frequently with water, or using of hand sanitizers for those who are using crutches and wheelchairs;*

*b) The social and safe distancing for those who are blind and on wheelchairs (…);*

*c) The feet-taps for those with physical disabilities;*

*d) Masks are a hindrance for those with sever cerebral palsy;*

* *People with sensory disabilities are among the most exposed to the risk of contamination during the current pandemic, and to the danger of death like people with intellectual and motor disabilities, in the context of emergency situations such as terrorist attacks, armed conflicts and climate disasters;*
* *Human rights defenders and organizations were not listed as first responders to the pandemic of Covid 19 by the governments, experiencing great limitation in their right of movement and in the possibility of a substantial intervention;*
* *Police was focused in ensure the respect of lockdown restrictions risking to lose the control of the rising phenomenon of Gender based violence;*
* *When the institutions couldn’t assist for persons with disabilities anymore, persons with disabilities were forced to leave such institutions without any adequate provision for their welfare or accommodation;*
* *Since the onset of Coronavirus pandemic, persons with psychosocial disabilities became more ‘invisible’ then ever, losing access to the limited services available and found themselves socially isolated;*
* *Persons with disabilities were disproportionately affected by the Covid-19 Pandemic thereby threatened to be institutionalized, during the first wave down in some urban areas street children and their families were rounded up and placed in institutions;*
* *Access to medical care became a challenge especially under restrictions of movement during of Covid-19 pandemic leading to delayed correction of some condition like hydrocephalus and “spinabifida” that require immediate attention;*
* *Persons with disabilities are excluded from some public hygiene services like hand washing stations, which are not disability friendly especially to wheelchair users;*
* *Most persons with disabilities don’t receive the aid provided by the government because either that they have not been informed of the date or place of distribution;*
* *Persons with Disabilities usually work in the informal sector, many of them need to beg in the streets, due to the lockdown they were deprived of their main resources issues in nutrition.*

***Recommendations:***

* *Governments should consult with and actively involve persons with disabilities in framing a right based response to the pandemic that is inclusive of and responsive to persons with disabilities;*
* *Community-based organizations, local authorities and public service providers should recognize that reducing the risk of disasters during emergency situations starts with making people aware and prepared to face a possible disaster;*
* *Ensure social security systems give individual support to prevent marginalization of Persons with disabilities during emergencies, through appropriate allocation of disability-inclusive budgets;*
* *Persons in institutions should have access to COVID-19 testing and subsequent treatment if infected, on an equal basis with others and without any form of discrimination, always respecting their dignity, autonomy, preferences and privacy;*
* *Mitigate the impacts of the pandemic in the community through mental health and psychosocial support and strengthen community resilience and preparedness.*

***Access to justice (art.13)***

***Concerns:***

* *Persons with disabilities need to be afforded with the full legal capacity and the economic support to face the cost of a trial in order to be able to make complaints.*

***Recommendations:***

* *It should be the duty of organization that works for persons with disabilities to ensure that legal framework is in place so that persons with disabilities will be safely protected from form of abuse.*

***Different forms of institutionalization, including isolation at family home and need to prevent them (art.14, 19, 28)***

 ***Concerns:***

* *Institutionalization is practiced as isolation while the person is at home and not in an institution as one of the major phenomena in Africa;*
* *Institutionalization also takes place in hospitals, mental health facilities, special schools, rehabilitation centres, religious facilities, etc.*
* *Persons with psychosocial disabilities are seen as objects of medication administration or project targets, this perspective gives reasons to institutionalize them;*
* *Psychosocial disability is often associated with criminality contributes to the incorrect perception that they are unable to function optimally in society and persons. Persons with psychosocial disabilities are often prevented from relying on their basic human rights;*
* *The process of devaluation of persons with disabilities consists in loss of opportunity, rejection, segregation, lack of choice, poverty, risk of abuse and socially devalued.*

 ***Recommendations:***

* *Apply a person-centred, social and a human rights model to recovery.*

***Structural violence against persons with disabilities in institutions (art. 15-16-17)***

***Concerns:***

* *Institutional care places persons with disabilities at risk of systemic and individual human rights violations because institutionalised persons are subjected to neglect, deprived of their liberty and they also experience other forms of severe restraint;*
* *Persons with psychosocial disabilities are suffering human rights abuses like caning, chaining, forced fasting, denial of freedom and independence of movement;*
* *Persons with disabilities in countries with a chronical internal instability and insecurity due to armed conflicts are subjected to a myriad of abuse, including unlawful killings, rape, forced marriage, and other forms of sexual violence, forced evictions; they are subject of limited access to health services, food and water, and other essential services;*
* *Women and girls with disabilities faced an increased risk of rape and other forms of sexual violence, often with impunity, due to perceptions they're disabilities where a burden to the family or that such persons were of less value and could be abused;*
* *Violence and sexual violence episodes targeting persons with disabilities are countless;*
* *Many reports, documentaries and cases investigated demonstrate the appalling conditions and abusive practices in many of our country’s special school hostels.*

***Recommendations:***

* *Prohibit the use of seclusion, restraint, use without consent of drugs or other treatments inflicting suffering and compromising the person's immune system, preventing restrictions on the use of the toilet, facilitate telephone or virtual contacts with family members and friends and carry out regular checks in these institutions in order to ensure compliance with the measures mentioned and to avoid any form of negligence, abuse or abandonment;*
* *Police personnel and the administration of justice should be trained to properly care for persons with disabilities who are at risk of or victims of violence, abuse or mistreatment;*

***Lack of recognition of the right of persons with disabilities to live independently and make choices (art.19)***

***Concerns:***

* *Society considers that persons with disabilities do not have the competence or capabilities to live independently. Persons with disabilities are perceived as being forever children who need assistance in every aspect of their lives;*

***Recommendations:***

* *There should be spiritual intervention, forgiveness and reconciliation to live amicably, counseling to bring understanding and acceptance to forget the past and focus on the future together as a family;*
* *Persons with disabilities should be actively encouraged to believe in themselves and aspire to be their best. Opportunities for this exists through the use of social media, technology and exposure to opportunities that can encourage the development of their innate abilities.*
* *Persons with disabilities should be informed of the provision of economic opportunities that can enhance their dignity and self-esteem. In turn, such opportunities will help to inform and enlighten the society about the possible contributions and worth of persons with disabilities.*

***Institutionalization negatively impacts on the scope of choice and self-determination of persons with disabilities (art.19)***

***Concerns:***

* *Institutionalization will either built fear, grow self-denial, develop negative attitude on persons with disability and even encourage physical and sexual abuse in the schools, prisons, special homes;*
* *At individual level, the mental health service user has so many barriers to effective living. Persons with disabilities struggle to have independence to make choices or do anything they would ordinarily do for themselves. The things that inhibit their living independent living goes as far as the kinds of medications they receive from the hospital which is always first generation drugs with all their side effects;*

***Individualized support (art.19 (b))***

***Concerns:***

* *Most employers working with persons with disabilities demonstrate a low interest to see the value addition a person living with disability will bring. This is because of the working culture, the inflexible hours, quantity instead of quality conception;*

***Recommendations:***

* *Ensure personal assistance, home care and rehabilitation services, where appropriate, which must be continuous to ensure the exercise of the rights of persons with disabilities, considering the importance of community support;*
* *Support persons with disabilities to have a “Meaningful Life During the Day”;*

***Equal access to services in the community (art.19 (c))***

***Recommendations:***

* *There should be policies which ensure constructing roads, building infrastructure and friendly to persons with disabilities;*
* *Assist persons with disabilities in developing friendships at work or at home;*
* *Ensuring access to education, work and employment, and empowerment of persons with lived experience to help facilitate independence and community inclusion;*
* *Begin to recruit persons with disability to work empowerment projects giving a sense of responsibility to youth with disability;*
* *Persons with disabilities need sports friendly playing grounds to participating in sports activities among the others.*

***Access to information (art.21)***

***Concerns:***

* *Information and communication are currently made in formats that are inappropriate and inaccessible to person with disability and to the part of the population living in the rural areas;*
* *Technology, while very important to help persons with disability in engaging with the community, lacks the personal touch that psychosocial support requires;*
* *Persons with disabilities face glaring inequalities when it comes to accessing such online platforms that offer peer support. This is largely due to the current economic status of low-income countries.*

***Education (art.24)***

***Concerns***

* *The medical model with its negatively associated segregation and institutionalization formed the methods the special schools dedicated to children with disabilities;*
* *Children with disabilities are studying in special schools rather than been integrated in regular schools;*
* *Persons living with albinism are particularly discriminated and are forced to drop out of schools;*
* *The decision to attend a special school is not a choice but always a necessity as in most cases local neighbourhood schools refuse to admit learners with disabilities or to provide them the necessary reasonable accommodations to be included. Parents must then remove their child from both their family and community to attend far off special schools in order to realise their right to education.*

***Recommendations:***

* *Ensure an inclusive quality education, especially for girls and adolescents with disabilities during quarantine, through online education and televised educational services, which must be accessible;*
* *Support or create higher education systems to include people with lived experience with mental health conditions in curricula to train health and mental health professionals;*
* *Children with psychosocial disabilities, such as autism should attend centres in the external system where they are picked up in the morning and distributed to their families at the end of the day;*
* *Leverage the use of technology in developing tools, learning materials and other solutions to enhance the core work of peer support workers.*

***Health (art. 25)***

***Concerns:***

* *Persons with disabilities are considered sexless and are deprived of sexuality, majority of them face challenges related to reproductive health rights;*

***Work and employment (art.27)***

***Concerns:***

* *Most governmental and non-governmental organizations seem unwilling to hire assistant for persons with disabilities and they use shortage of finance for their refusal;*

***Recommendations:***

* *Identify and acknowledge the gifts persons with disabilities have in order to offer the opportunity to have a meaningful job.*

***Data (art.31)***

***Concerns:***

* *Lack of statistics or comprehensive information on the number and situation of people with disabilities that cause limited awareness of disability issues among policy makers, planners, community leaders, services providers and the general public;*
* *Reinforce the capacities of monitoring the protection of the organizations of persons with disabilities helping the countries to set up a permanent monitoring system in line with the CRPD Convention.*

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