## **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 the Middle East and North Africa (MENA)**

1. ORGANIZATIONAL MATTERS

(a) Logistics and organizational matters:

The consultation took place online and the programme (see annex) included two segments of one hour each, in which 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. Ms. Soumia Amrani, a Committee member, moderated the discussion. Ms. Amalia Gamio and Mr Robert Martin, attended the consultation as well.

The language of the meeting was Arabic and interpretation into English was available. International Sign and captioning were provided.

(b) Participants in the regional consultations:

54 participants attended the online consultation, including 22 speakers, 21 observers, three Committee members and members of the Secretariat. The Committee received 26 written submissions and three video statements, in which two were played during the consultation.

Through the online consultation and by submitting written submissions, persons with disabilities from the following countries were represented:

Egypt; Iran; Iraq; Jordan; Lebanon; Libya; Morocco; Saudi Arabia; Sudan

Syria; United Arab Emirates; Yemen; and the occupied Palestinian territories.

Groups represented included: women and girls with disabilities; persons with autism; persons who are deaf, persons who are deafblind; persons with psychosocial disabilities; persons with intellectual disabilities; and children with disabilities.

1. **CONCERNS AND RECOMMENDATIONS OF ACTION**

The following is a summary of concerns raised by participants that the Committee should include in the Zero Draft Guidelines for the Deinstitutionalization. To facilitate the reading, concerns and recommendations are grouped under headings related to the provisions of the Convention.

***Discriminatory policies and practices (art.1)***

***Concerns:***

* The prevalence of the medical model and chairty model to disability in the society and legislative framework or the weak implementation of the human rights based model;
* Isolating persons with disabilities in the private sphere, particularly by their families;
* Many persons with disabilities are usually living in extreme poverty, without access to education, employment, housing and social protection benefits. This situation result in making persons with disabilities dependent on support by their families or facing homelessness;
* Lack of support and assistance to persons with disabilities, including personal assistants, to enjoy the right to independent living, which is associated with the fact that services are only provided in institutions.

 ***Recommendations:***

* Ensure the implementation at all levels of the human rights-based model to disability and abolish the medical and charity models in the legislation and in practice;
* Provide support services, including personal assistance, necessary to support independent living and inclusion in the community for persons with disabilities;
* Ensure the enjoyment of persons with disabilities of social protection schemes and benefits and guarantee their access to employment, housing and education at all levels;
* Establish national funds to provide support services to persons with disabilities, as an urgent response plan;
* Provide support to families of children with disabilities and ensure the access of children and their families to support services, particularly educational and psychological support and social protection funds.

***Legislation and public policies, including implementation (art.4)***

***Concerns:***

* *The right of living independently is not reflected in national legislation;*
* *Absence or weak internal monitoring mechanisms for the implementation of the Convention and the right to independent living.*

***Recommendations:***

* Criminalize all forms of institutionalization, with a particular focus on isolation in family houses;
* Ensure adequate resources, particularly financial resources, to implement the deinstitutionalization process and end any financial support to institutions;
* Establish independent monitoring mechanism for the implementation of the legislative and policy frameworks on deinstitutionalization, with the participation of persons with disabilities.

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

***Concerns:***

* Lack of consultation with persons with disabilities in the design, development and implementation of laws, policies and programs on disability;
* Low number of organizations of persons with disabilities due to lack of financial support for such organizations and lack of awareness among persons with disabilities on the work and existence of such organizations;
* Weak representation of persons with disabilities in decision making and leadership positions in civil society organizations.

***Recommendations:***

* Conduct consultations with persons with disabilities and organizations of persons with disabilities in relation to the design and implementation of laws, policies and programs on disability;
* Ensure the participation of organizations of persons with disabilities in the assessment and evaluation of policies and programs targeting persons with disabilities;
* Facilitate the registration of organizations of persons with disabilities and provide financial support and capacity building to carry out their activities and their outreach to persons with disabilities;
* Ensure the participation of persons with disabilities and organizations of persons with disabilities in the design, implementation and assessment of the deinstitutionalization process;
* Conduct an outreach action plan to ensure the participation in the deinstitutionalization process of persons with disabilities in institutions and those isolated in the private sphere by their families.

***Non-Discrimination (art.5)***

***Concerns:***

* Persons with disabilities face stigma and discrimination which limit their enjoyment of their rights and lead to their isolation and exclusion from their societies;
* Discrimination on the basis of disability is not criminalized and persons of disabilities are not protected.

***Recommendation***

* Criminalize discrimination based on disabilities and provide protection for persons with disabilities as well as ensure the availability and accessibility to complaint mechanisms;
* Carry out raising awareness initiatives targeting the public and State officials on the human rights model to disability to combat prejudice and stigma against persons with disabilities;
* Provide capacity building and raising awareness for families of persons with disabilities on the rights of persons with disabilities;
* Target children with disabilities to inform them about their rights and to allow them to take decisions.

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

***Concerns:***

* Women with disabilities are less represented in organizations of persons with disabilities and there are few organizations of women with disabilities, which impacts their participation and consultation in developing and implementing laws and policies;
* Women and girls with disabilities are often victims of gender-based violence in institutions and for those who are home-isolated. Theses assaults and abuses are faced with impunity as there is no accessible reporting mechanisms and due to the stigma to file complaint against such violations and abuses;
* Women and girls with disabilities who are home-isolated are forced into domestic work.

***Recommendations:***

* Ensure that women and girls with disabilities effectively participate and involve in the planning, implementation and monitoring policies regarding persons with disabilities, including through organizations of women with disabilities;
* Ensure a safe environment for women and girls with disabilities and protect them from all forms of violence, abuse or mistreatment, as well as the provision of accessible complaint mechanisms.

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

***Concerns:***

* Children with disabilities are often abandoned by their parents in institutions or home isolated and prevented from interacting with others, including family members;
* Children with disabilities are enrolled in segregated education facilities or not provided with education due to the lack of inclusive education and lack of accessibility;
* Children with disabilities are not consulted in matters related about their lives.

***Recommendations:***

* Criminalize institutionalizing of children with disabilities by their families and provide children with disabilities and their families with adequate support services;
* Conduct raising awareness on the importance of consulting and involving children with disabilities in taking decisions;
* Ensure the availability of inclusive education in schools the accessibility of children with disabilities*.*

***Effect of the COVID-19 pandemic or other emergencies (art.10-11)***

***Concerns:***

The ongoing COVID-19 pandemic revealed the fragile reality for persons with disabilities and the impact of not adopting inclusive responsive measures. In some cases, persons with disabilities were locked in institutions and further isolated from the society with poor services provided and high infectious rates. In other cases, institutions were shut down without providing persons with disabilities with support services or alternative accommodation and sending them to their families or leaving them facing homelessness. Inaccessible information and the lack of accessible health care services increased the vulnerability of persons with disabilities.

In terms of humanitarian emergencies and conflicts in the region, persons with disabilities are often left behind in harsh situation without any support services, as the provision of such services stops immediately by the Government. Humanitarian assistance by external stockholders are usually inaccessible to persons with disabilities. Displacement of civilians severely impacts persons with disabilities as they become dependent on others without the provision of any support services by any entity.

***Recommendations:***

* Ensure the effective participation of persons with disabilities in designing and implementing inclusive emergency response;
* Adopt measures to ensure the continuation of support services during emergency situation, particularly accommodation, health care services, social protection and education;
* Provide information in accessible formats by public and private media outlets;
* International and local non-governmental organizations and humanitarian relief agencies should ensure the inclusion of persons with disabilities in their response programs and assistance through direct consultations and accessible services and assistance.

***Equal recognition before the law (art.12)***

***Concerns:***

*The guardianship system deprives persons with disabilities, particularly persons with intellectual disabilities and persons with psychosocial disabilities from their right to be equally recognized before the law, which increases their vulnerability and exclusion from their societies.*

***Recommendations:***

* Legally abolish the guardianship system, as well as in practice, to guarantee the equal recognition of persons with disabilities before the law;
* Design and provide supported decision-making systems that are respectful of the autonomy, will and preferences of all persons with disabilities.

***Persistence to institutionalization and need to prevent it (arts.14, 15, 16, 17, 19, 28)***

 ***Concerns:***

* Persons with disabilities are institutionalized at young age due to different factors: poverty, wrongly assuming disability as illness, lack of adequate support services, stigma and prejudice against persons with disabilities in the society, not being recognized before the law. Institutionalization is perceived as a ‘solution’ and a ‘form of protection’ for persons with disabilities in lack of support services and inability of families of ‘taking care’ of persons with disabilities. Persons with intellectual disabilities and persons with psychosocial disabilities are particularly vulnerable to long term institutionalization and subjected to medication under unconditional authority of medical staff.
* Institutions are not monitored and admission persons with disabilities is not regulated;
* Persons with disabilities are subjected to different forms of abuses, neglect, overmedication and completely isolated for the society.

 ***Recommendations:***

* Criminalize institutionalization of persons with disabilities in institutions and by their families (home isolation);
* While implementing a deinstitutionalization process, adopt regulation to prevent admitting persons with disabilities into institutions and monitor institutions and the situation of persons with disabilities.

***Understanding of independent living and self-determination (art.19)***

***Concerns:***

* Due to prevailing medical and charity model for disability, there is conception that persons with disabilities do not have the competence or capabilities to live independently as they need assistance in every aspect of their lives.

***Recommendations:***

* Raising awareness and outreach campaigns by the Governments and the organizations of persons with disabilities to inform persons with disabilities about their right of independent living and the support services to be made available to exercise this right;
* Persons with disabilities, particularly children with disabilities, should be able to make decision about all aspects of their lives independently, including where to live and with whom.

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

***Concerns:***

* The concept of personal assistant to persons with disabilities does not exist or poorly implemented in the region.

***Recommendations:***

* Develop concepts for the provision of individualized support, in consultation with persons with disabilities, and raise awareness about such services.

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

***Concerns:***

* Inaccessible information and communication for persons with disabilities lead to further isolate them and exclude them from their societies.

***Recommendations:***

* Ensure the availability of accessible information and communication for all persons with disabilities.

***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.

***Recommendations:***

* Develop a comprehensive data collection system on persons with disabilities, with the participation of persons with disabilities.

***International cooperation (art. 32)***

***Recommendations:***

* Ensure that international development projects are inclusive to persons with disabilities and particularly aim at empowering persons with disabilities and do not lead to institutionalization of persons with disabilities;
* Ensure the effective participation of persons with disabilities on the design and implementation of projects by international development donors.

***National implementation and monitoring (art. 33)***

***Recommendations:***

* Ensure the effective and independent monitoring of the implementation of Convention, as well as laws and policies, with the involvement of persons with disabilities.

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