

**CBM submission to the UN Committee on the Rights of Persons with Disabilities regarding the draft General Comment on Article 19 “Living independently and being included in the community” of the UN Convention on the Rights of Persons with Disabilities**

CBM welcomes the opportunity to provide comments to the draft General Comment on Article 19 of the UN Convention on the Rights of Persons with Disabilities. We recognize the right to “living independently and being included in the community” as a key aspect for persons with disabilities to be included in society, promoting their own personal development and contributing to a more diverse and inclusive society.

Poverty and disability

CBM expertise is based on its work towards the inclusion of persons with disabilities in the poorest communities of the world. Therefore, we welcome the recognition that the majority of persons with disabilities live in conditions of poverty and the fact that the Committee stressed the need to address the negative impact of poverty **(Paragraph 5)**. The proven cycle between poverty and disability shows **the need to include the rights of persons with disabilities in development policies and programmes[[1]](#footnote-1)**, including the full and active participation in the community. An estimated 80% of persons with disabilities live in developing countries, facing lack of resources but also a higher risk of discrimination due to attitudinal barriers towards disability. This is **especially challenging for women and girls with disabilities, who face multiple discrimination, lack of access to specific support and rights as well as attitudinal barriers towards their role in the community**. Violence against women and girls with disabilities can decrease through their empowerment and their recognition as active members of the community.

In this regard, States parties should not add to the hardship faced by persons with disabilities, by reducing their income in this period of austerity measures **(Paragraph 5)**. In the context of budget cuts and austerity measures, we would particularly like to stress that States parties should maintain basic social support for those citizens who face more vulnerable situations. **Budget cuts that affect persons with disabilities more than the average population** or even specifically target budget provisions for persons with disabilities, are in contradiction with human rights law in general and the Convention in particular.

The role of international cooperation and the 2030 Agenda for Sustainable Development

CBM welcomes the reference to the 2030 Agenda for Sustainable Development **(Paragraph 13)** in addition to The New Urban Agenda (Habitat III). The adoption of the UNCRPD in 2006 and the continuous efforts of the disability rights movement have led to improved awareness among political and civil society stakeholders. **This awareness raising must also reach other international frameworks such as the Sendai framework for Disaster Risk Reduction or the Paris Agreement on Climate Change.** These international frameworks aim to eradicate poverty by respecting the planet and its natural resources, highlighting human rights as the only way to achieve a sustainable change.

As the international community is taking steps to implementation the 2030 Agenda, **it is important that the UNCRPD and other human rights conventions guide the implementation plans**. The implementation needs to be comprehensive and to prioritize effectively those left furthest behind. The 2030 Agenda, the New Urban Agenda and Sendai have to be understood in the light of human rights in their **universality** and their nature of being **indivisible, interdependent and interrelated**. The Agenda is a milestone on the way to sustainable development. It can largely contribute to inclusion and the realization of human rights for persons with disabilities. It is the political framework of the moment, while the overarching human rights system goes well beyond the time horizon of 2030 and has a vision that goes beyond immediate priority areas as defined by the SDGs.

International Cooperation investments and projects should not contribute to the perpetuation of barriers to independent and community living **(Paragraph 66)**. In order to support independent living choices of persons with disabilities **all new objects, infrastructure, facilities, goods, products and services must be fully accessible for all persons with disabilities (language from CRPD/C/GC/2**).

According to the **Paragraph 93**, all international cooperation (art. 32) must be conducted in a way which ensures that foreign aid is invested in support services in local communities that respect the will and preferences of persons with disabilities and foster their right to choose where, with whom and under which living arrangements they will live in line with article 19. In this regard, CBM would like to bring the attention regarding those **barriers faced by women with disabilities in having control and choice over their lives due to cultural norms and values**. This gap must be addressed as part of a gender sensitive and disability inclusive approach by donors and international stakeholders.

Diversity of persons with disabilities

The CRPD recognizes the “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity” as a core principle of the Convention. Following the reflection of the diversity of cultural approaches to human living **(Paragraph 8)**, there is a need for States Parties to **provide different resources, systems and mechanisms** that can be adapted to the different needs and choices of persons with disabilities. This is particularly important for **persons with intellectual, learning and psychosocial disabilities, persons in need of high levels of support or persons with multiple disabilities** (e.g. deafblind persons).

CBM recognises the fact that different cultures can also challenge the concept of Independent living in accordance with the Convention **(Paragraph 21)**. The example given in the Draft General Comment addresses organisational culture, specifically how institutions approach a care system for young persons with disabilities when they live in institutional settings for elderly people. However, CBM would like to raise that **full and active participation of persons with disabilities in the community is linked as well with the cultural conception of community**. This is why it is important to **contextualize the situation when planning different systems by which persons with disabilities can achieve their independence and autonomy**.

In this regard, we welcome the reference by which different cultures can also challenge the concept on Independent living in accordance with the Convention **(Paragraph 22)**. CBM would like to highlight the need to **review the concept of “culture”** and how it is **important for persons with disabilities to interact with the culture of their choice**. **Independent living needs to be culturally contextual**. The concept of culture and its implications should be defined by persons with disabilities and DPOs rooted in these communities.

De-institutionalisation as the way forward

In many countries, persons with disabilities have traditionally been institutionalised by government and local authorities, especially for individuals with high demands for personal assistance and/or community support **(Paragraph 20)**. This is also relevant for **persons with intellectual and psychosocial disabilities**, who face attitudinal barriers due to **stereotypes and misconceptions about their capacity to contribute positively to family and community life**. In addition, when **individuals and families do not have community support options, together with the lack of resources to organise these supports**, the result is that persons with disabilities end up in institutions as a result of various pressures. This is exacerbated by the situation in some countries in which institutionalisation is the most extended and funded mechanism.

One of the key aspects of Article 19 is, however, the right for “persons with disabilities to choose their place of residence and where and with whom they live”. For that reason, we welcome the call for States parties to adopt a strategy for de-institutionalisation **(Paragraph 56)**. Institutionalisation should no longer be an individual’s first choice. On the contrary, it should be **based on community support, personal assistance or other similar mechanisms should be in place, funded and provided by States Parties, together with awareness raising campaigns which promote attitudinal changes towards the role of persons with disabilities in the community**. Personal assistance and community level supports are not the only systems to approach de-institutionalisation, but it has been proved to be the most cost effective financial investments for States parties.

In order to ensure freedom of choice and wellbeing, **transition mechanisms** should be in place for persons with disabilities coming from institutions to adapt and feel comfortable when being included in the community. For instance, the system of transformation that needs to be in place must count on housing policies that are inclusive and accessible to persons with disabilities. This must be done by **empowering persons with disabilities**, **building capacity** of their representative organisations and **promoting the general principles of the UN Convention on the Rights of Persons with Disabilities**. States Parties should **consult with organisations of persons with disabilities** in order to understand their needs and how they should be supported for their full and active participation in the community. States parties must consult persons with disabilities and their representative organisations when **planning, implementing, monitoring and evaluating** development cooperation programmes to ensure coherence with the UN CRPD, including programmes on **urban and rural development** as well as other issues related to the right of living independently and to be included in the community. In addition, when organizing participatory and consultative processes, States parties need to **respect human diversity** and involve persons from various impairment groups and ensure the **participation of women and girls on an equal basis with men and boys**.

Particular attention should be given to the promotion and protection of the rights of women with disabilities, especially regarding their **sexual and reproductive health and rights (SRHR)** as well as **establishing mechanisms to avoid violence against women and girls with disabilities** from personal assistants or any community support system. This should be done guided by the principles of the CRPD and the CEDAW.

Independent living has been one of the most demanding mechanisms among persons with disabilities and their representative organisations. Through this mechanism, persons with disabilities can choose a support, such as a personal assistant, by which their decisions can be realized. **This support can be as well a trustworthy and reliable person with whom a person with intellectual disability can take decisions based on accessible information and consultation.** For instance, an assisted decision-making system should be provided to persons with learning disabilities, through a trust-worth person elected by the person with disability. In this regard, States parties would develop a system more aligned with the CRPD to eliminate guardianship.

Human Rights Based Approach

Freedom of choice is being denied for persons with disabilities. Among them, persons with intellectual and/or psychosocial disabilities face even more discrimination as decision makers, due to the social perception of their lack of capacity to choose. In this regard, disability support services must be available, accessible and acceptable to all persons with disabilities **(Paragraph 58)**. There is a need to protect, fulfill and promote the rights for those persons with disabilities who face multiple discrimination based on **income, gender, age, race, ethnicity, migratory status, geographic location and other characteristics relevant in national contexts**[[2]](#footnote-2).

Adopting a human rights based approach, bearing in mind the rights of persons with disabilities as enshrined in the CRPD as one of the core human rights conventions, will ensure that States Parties promote policies and practices fighting against discrimination and inequity. **It is in the nature of human beings to belong to a community, to socialize and to actively participate in society**. States Parties must prevent isolation of all persons with disabilities for them to enjoy a right which has been denied for the most part of our History.

Empowering persons with disabilities through inclusion

There is still a gap between the goals and the spirit of article 19 and the scope for its implementation **(Paragraph 14)**, including negative attitudes, stigma and stereotypes that prevent persons with disabilities from being included in the community and accessing available support. Persons with disabilities often are deprived of their right to choose, due to attitudinal discrimination and **prejudices regarding** **their capacity to take an informed decision**. In order to live independently and be included in the community, **persons with disabilities must be recognized as decision makers, with the power of taking decisions and with the right to learn from their own mistakes**. This links directly with Article 12 “Equal recognition before the law”.

Independent and community living **(Paragraph 85)** are inherently linked to inclusive education (art. 24) health care (art. 25), rehabilitation (art. 26) and work and employment (art. 27). In order to live independently and be included in the community, **women and men with disabilities must be given the opportunity to be included in the regular labor market, they must have the right to control their own money and resources and use it freely, based on an informed decision**.

Data and monitoring

States parties should establish monitoring mechanisms of service providers, adopt measures which protect persons with disabilities from being hidden in the family or isolated in institutions, protect children from being abandoned or institutionalized on the grounds of disability and establish appropriate mechanisms to detect situations of violence against persons with disabilities by third parties **(Paragraph 51)**. De-institutionalisation process must ensure that **persons with disabilities are provided with a proper support with the aim to have an active participation and inclusion in the society**. States parties should **consult with persons with disabilities and their representative organisations** to guarantee that the de-institutionalisation process is aligned with the CRPD.

In order to provide accountable and reliable data, States parties **should gather data information on the process of de-institutionalisation**, as one of the main priorities to implement art. 19. This will guarantee the development of **useful monitoring mechanisms to provide effective follow-up of the de-institutionalisation process**. This data collection should be disaggregated by income, gender, age, race, ethnicity, migratory status, geographic location and other characteristics relevant in national contexts.

Related to the data and monitoring system, **(Paragraph k)** independent monitoring mechanisms and National Human Rights Institutions operating under the Paris Principles play an important role and should be given sufficient resources. States parties should, as part of the same monitoring mechanism, **report regularly on the de-institutionalistion process**, showing evidences on the number of women, men, girls and boys with disabilities living in accessible living arrangements that respond to their own choices.

Art. 19 UNCRPD in the context of humanitarian situations

Among refugees and Internally Displaced Persons (IDPs), there is an important percentage of persons with a disabilities. While exact figures are difficult to obtain due to deficient registration and identification processes, studies show that prevalence can become as high as over 20 percent for persons coming out of a situation of war or disaster[[3]](#footnote-3). Physical and mental trauma caused by humanitarian crises may additionally lead to impairments and ultimately disabilities.

Refugees and IDPs with disabilities are significantly less in control and have fewer choices than persons without disabilities in the same situation when it comes to living arrangements and access to basic services. Refugee camps often do not provide accessible health, WASH, education, transport etc. services for persons with disabilities. Women and girls with disabilities in refugee camps face additional challenges, they are particularly vulnerable due to low standards of security and hygiene.

The situation for refugees and IDPs with disabilities living outside refugee camps, in urban areas, often is worse. Persons with disabilities have even less access to basic services and are often unaccounted for. Their disability status and location is often unknown to the authorities. Children with disabilities in these informal urban refugee living arrangements often do not have access to school.

States parties, national and international stake holders need to improve registration and identification processes and increase the availability of accessible shelters and accessible basic services for persons with disabilities in refugee situations. While choices for refugees and IDPs are generally limited in humanitarian situations, further limitations for persons with disabilities in choice and control must be avoided. States Parties and international and national stakeholders need to include persons with disabilities in emergency planning and in the management of refugee camps and other shelters for refugees and IDPs to ensure that persons with disabilities enjoy their right to live independently and be included in the community on an equal basis with others.

1. CBM publication [“The economic case for disability-inclusive development”](http://www.cbm.org/article/downloads/54741/DID_series_2_-_Inclusion_Counts__coming_soon_.pdf) shows the social and economic positive impact for society to be more diverse and to include persons with disabilities. [↑](#footnote-ref-1)
2. Language taken from the 2030 Agenda for Sustainable Development [↑](#footnote-ref-2)
3. HelpAge and HI, Hidden victims of the Syrian crisis, disabled, injured and older refugees, 2014. <http://www.handicap-international.us/hidden_victims_of_syrian_crisis> [↑](#footnote-ref-3)