

Transforming Communities for Inclusion (TCI)

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**Submission made by:
Transforming Communities for Inclusion (TCI)**

**Transforming Communities for Inclusion contribution to the call for submission from the
Committee on the Rights of Persons with Disabilities on the Day of General Discussion (DGD)
Article 11 of CRPD**

Transforming Communities for Inclusion (TCI) is a global organization of persons with psychosocial disabilities. TCI forecasts a future in which all human rights and full freedoms of persons with psychosocial disabilities are realized. We are guided by the United Nations Convention on the Rights of persons with Disabilities (UNCRPD). We are the largest representative voice of persons with psychosocial disabilities, having members from 50 countries globally.

We define ‘psychosocial disabilities’ inclusively: persons who identify as with psychosocial disabilities, users and survivors of psychiatry, persons with intersectional, neuro-diverse identities, autistic persons, persons attributed a ‘mental illness’, persons deemed to be of ‘unsound mind’, etc. who continue to be marginalized in the society, are at risk of institutionalization and their voices are still unheard of in highest level policy circles.

TCI has been working with member organizations, where Article 11 of the CRPD has been a key thematic area. The CRPD Committee adopted the “Guidelines on De-institutionalization, including during emergencies” (A/HRC/C/5) in October, 2022. This gave visibility and direction to the situation of underrepresented groups, especially during times of humanitarian emergencies and disasters. Following this, we highly appreciate the CRPD monitoring committee develop a General Comment on Article 11 of the CRPD.

Other than contributing to the Guidelines through the Global Coalition on De-institutionalization¹, TCI has continued advocacy for access to enabling legal frameworks, inclusive community services and support systems, and full participation in Development, as required by persons with psychosocial disabilities to live independently in the community². TCI partnered with several of its members during

¹ <https://gc-di.org/about/>

² CBM, IDA, PDF, & DFAT. (2022). *OUR LESSONS_ AN APPROACH TO DISABILITY-INCLUSIVE DISASTER RISK REDUCTION – BASED ON CONSULTATIONS WITH PEOPLE WITH DISABILITIES IN THE ASIA AND PACIFIC REGIONS*. Available at: <https://www.cbm.org.au/wp-content/uploads/2022/07/CBM-Inclusion-Advisory-Group-IG-Our-Lessons-report-May-2022.pdf>

the Pandemic by providing grants to keep communities together providing rations, safety, digital, social and psychosocial supports and linkages to services³.

In developing this submission TCI draws from its work on Article 11, COVID experience shared by members, and Focus Group discussions conducted with national lead members towards the General Comment.

I. Introduction

[Please indicate the main challenges experienced by persons with disabilities in the field of your organization's expertise or the area of international law you work on].

Persons with disabilities, particularly those with psychosocial disabilities, are discriminated in society. They are discriminated and excluded as persons with 'mental illnesses', mental patients, persons of 'unsound mind', 'mad' persons, etc. This poses intractable attitudinal, legal, social, economic, cultural and program barriers to access opportunities, take risks, make their own decisions, have their will and preference respected, or enjoy all fundamental human rights for living independently and on an equal basis with others⁴.

Persons with psychosocial disabilities are frequently shackled legally, by incapacity laws, mental health laws and a wide variety of civil laws, through 'civil commitment procedures' (e.g. through Vagrancy law). They are stripped of their personhood and their right to identity, further exacerbated through guardianship and conservatorship laws. 'Non-persons' do not have any rights in society, including the right to access justice: They are the 'civil dead'. As they are non-persons, they are not seen as requiring reasonable accommodations at the individual level. The impact of being civil dead on lives of persons with psychosocial disabilities is total disqualification from political participation, family life, work and employment, education, etc. This impacts how they are treated during humanitarian emergencies and disasters.

[GC for Article 11 should recognize that], Such groups, already marginalized to the most severe extent of not having personhood, are likely to be disproportionately affected and excluded in actions and plans before, during and after humanitarian crises and disasters. GC for Article 11 should detail their exacerbated risk to violence, abuse, inhuman, cruel and degrading treatments, shunting between different institutions (trans-institutionalization) and losing their life and liberty.

In more than one country (as reported by TCI membership), people with psychosocial disabilities imprisoned inside institutions and asylums are abandoned during disasters. There are several instances of accidents and deaths in such places⁵. In situations of emergencies, families and communities seek safer ground, while those institutionalized perish inside custody^{6,7}. During the pandemic, several custodial institutions shut their doors completely to the outside world and there is

³ TCI. *COVID 19 Microgrants Program: Final Report*. (2021). Available at <https://tci-global.org/wp-content/uploads/2022/05/Final-Report-COVID-19-Micro-Grants-1.pdf>

⁴ A/HRC/37/56 (Report of the Special Rapporteur on the rights of persons with disabilities)

⁵ Fire accidents, flooding and other such localized disasters are known inside institutions (Sri Lanka, India, Japan, Indonesia, Philippines, etc.)

⁶ "In Indonesia during the 2018 earthquake, it was reported that a young person with psychosocial disability who was released from a mental asylum was shackled by his family inside the home. During the earthquake situation and emergency, he was left behind by the state, community and his family members during the evacuation process. Luckily the person survived as the home where he was shackled was not made of concrete but was a wooden house". Participant to a TCI FGD on the General Comment on Article 11.

⁷ IMHA. (2018). *Indonesian Mental Health Association Investigation in Palu, Central Sulawesi. The condition of people with psychosocial disability who lived in confinement or shackling, during and post-disaster in Central Sulawesi*. Available at <https://tci-global.org/wp-content/uploads/2022/05/Indonesian-Mental-Health-Association-Investigation-in-Palu-Central-Sulawesi.pdf>

no data on how many survived the pandemic. Persons, especially children with mental, intellectual disabilities, autistic persons, women, girls and elderly with physical and mental disabilities are often found lumped together in such custodial spaces, abandoned by families.

During the situation of humanitarian emergencies and disasters, institutionalized people with disabilities lack access to information in accessible and easy to understand formats. For e.g., there are so many people with psychosocial disabilities living with hard of hearing issues or are deaf and rely on sign language interpretation⁸.

People with psychosocial disabilities are committed against their will to mental institutions, asylums, rehab centers, nursing homes, social care institutions, half way homes, de-addiction centers, group homes, shelters, camps and other a variety of institutions. Even if such custodial places were not already prevalent before disasters, a variety of institutions and aggregated living arrangements are built post-disaster, as a way of 'building back better'. In post disaster scenarios, for example, in Sri Lanka, India^{9,10}, Malaysia, Kenya, Indonesia, humanitarian aid is used by the state, INGOs and other development agencies for the *improvement of the mental asylums and institutions* often advertised as 'state of the art' facilities, instead of investing in community support and community services.

Forced Psychiatric treatments is given to persons with disabilities, particularly those in institutions. Over-drugging and shock treatments are common. The drugs have many side effects: They lower stamina, making persons numb, not only mentally but also physically. Poor hand leg coordination, reduced gross and fine motor movements, a stiff and wooden gait, loss of speech, Parkinsons' like conditions, obesity and sedation are frequently experienced, impeding quick movement. Especially institutionalized children have lost their childhood, health and wellbeing to these treatments, often being sedated and sleepy. Not having access to psychosocial supports, good nutrition, sport and access to different mainstream services, low possibility of recovering to a state of good health and wellbeing, and low physical strength makes it difficult to evacuate persons with psychosocial disabilities during situations of humanitarian emergencies and disasters. Safe places created for communities during floods, tsunamis, typhoons and other disasters are on higher ground or far away from disaster-prone areas. For people with psychosocial disabilities who have less physical strength and / or elderly people on lifelong drugs have no recourse to escape.

During the evacuations when disasters occur, people with intersectional and neurodiverse identities, especially from the LGBTQI community, are commonly left behind because they have not been accepted in mainstream society. The families of people with psychosocial disabilities from the LGBTQI community take advantage of such situations and leave them behind under hazardous conditions.

People with psychosocial disabilities in institutions have poor immune systems due to poor nutrition and high dosage psychiatric drugs, bad health care, and no access to sanitation. During the COVID Pandemic, persons with psychosocial disabilities in institutions were at greater risk of the infection

⁸ "In Fiji, members of Psychiatric Survivor Association were not included in the preparedness and disaster risk reduction activities. Aa Thunderstorm hit Fiji in 2018 and people with psychosocial disabilities did not have access to the information of evacuation program organized by the local government. They had no clue where the safe place was created and the location of the evacuation center." Participant to a TCI FGD on the General Comment on Article 11.

⁹ For example, in India (2001), following the death of 25 persons with psychosocial disabilities due to a fire accident, the Supreme Court issued an order for the construction of more asylums, prescribing at least 1 asylum per district. Fortunately, the government budgets do not allow such infrastructure costs. However, Tamil Nadu, India, where this incident happened has the highest number of closed-door institutions.

¹⁰ Davar, B. (2012). *Legal Frameworks for and against People with Psychosocial Disabilities*. 47(52).

<https://www.epw.in/journal/2012/52/special-articles/legal-frameworks-and-against-people-psychosocial-disabilities.html>

and mortality as institutions became a 'petridish' for the cultures to flourish. They cannot maintain social distancing, had no access to sanitation measures, nor accessible information COVID¹¹.

During the COVID Pandemic and humanitarian emergencies persons with psychosocial disabilities living in lockdown and curfew situations in their homes and communities, lose all social support systems, response services, personal assistance, peer supporters, and their social capital. During evacuation their distress and disability is aggravated.

Persons with psychosocial disabilities, children, women and girls with disabilities have no access to meaningful occupation, education, access to health care, nutrition, and other such basic amenities needed for life, on equal basis with others in the reconstruction period. Persons with disabilities staying in camps and evacuation centers are left to their own devices and resources, rather than seen as needing specific disability assistance or general services. During drought and famine situations, persons with psychosocial disabilities are allowed to die due to starvation, because they are the last ones to get food and water in camps¹². It has been reported that persons with psychosocial disabilities, particularly women, who are 'non persons' are exploited during rescue operations as 'mules' to carry food, medicine and supplies between disaster zones, camps and households¹³. Practices of violence, abuse and sexual exploitation of women and girls with psychosocial disabilities occur in evacuation centers and camps¹⁴. As the persons are 'non persons', they have no recourse to justice, first responders and the police do not believe them.

During preparedness there are number of capacity building initiatives taken by humanitarian organizations. Individuals with psychosocial disabilities and our organizations are not included in capacity building and training initiatives. These capacity building opportunities include trainings on evacuations, responses, creating safe places, humanitarian programs cycles, and legal systems.

Unfortunately, due to subject to institutionalization and medical approach to psychosocial disability, we are completely left behind throughout the capacity building processes. Capacity building focuses on 'mental health' rather than 'inclusion', restricting the trainings to the medical model and coercive frameworks. People with psychosocial disabilities have no access to information and communications related to the any trainings nor involved in the process. OPDs lack capacity and also in many countries only a few organizations of persons with psychosocial disabilities exist. Even the organizations exist are hardly, involved in any capacity building programs by cross disability stakeholders, national disaster managements or UN agencies.

During disasters, people with psychosocial disabilities are not included in the data collection processes. There is a clear correlation between data, analysis and needs assessments during a response period. The data collection questionnaire/tools totally exclude us, and we are always left behind in all national counting's. This restricts the inclusion of persons with psychosocial disabilities in response programs, and access to any social protection schemes being offered during disasters which results in no access to cash transfers, aids, and in-kind support.

Many countries still do not have comprehensive policies that include all persons with disabilities, or use derogatory and discriminatory language in them. All national focal bodies for humanitarian

¹¹ DRI, IDA, ENIL, CHR UoPretoria, Validity Foundation, DRF, & IDDC. (2020). *Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor*. Available at: <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>

¹² Reported by TCI members in Africa [TCI FGD on GC on Article 11].

¹³ It was reported by TCI members that in Fiji, during the humanitarian settings such as evacuation centers, people with psychosocial disabilities were used as a means to carry things from one place to another and also to go in the disaster prone areas to transport the belongings of the families to evacuation centers. [TCI FGD on GC on Article 11]

¹⁴ A/72/133 (Sexual and reproductive health and rights of girls and young women with disabilities)

actions, public health control authorities and disaster planning authorities should review their plans, policies and budgets for disability inclusion with the participation of representative OPDs. Monitoring and Evaluation indicators must include disaggregated data on responsiveness of the system and interventions to disability inclusion.

II. Normative Content

[Under the following relevant subparagraphs, please develop narrative on the scope and meaning of the following terminology of article 11 of UNCRP, from the point of view of your organization and field of expertise]

- a) " States parties shall take measures, in accordance with their obligations under international law, including international humanitarian law and international human rights law.

Humanitarian emergencies and disasters should not be an excuse for states parties and stakeholders to "exercise any distinction, exclusion or restriction having the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights of all persons with disabilities". [Sections VII(E) of General Comment 6 on Equality and Non-Discrimination is relevant and be adapted into this text¹⁵].

The Guidelines on De-institutionalization, building on GC 1, GC 5, GC 6 among others, organizes detailed guidance for state party actions during humanitarian emergencies and natural disasters, by providing multi-pronged actions on [1] enabling legal frameworks; [2] preparation for living life in the communities and leaving institutions; [3] support systems and support services that should be available in communities; [4] and finally, access to a range of mainstream services. The text of the Guidelines could be elaborated that "The exercise of the rights under article 19 of the Convention cannot be suspended in situations of emergency, including in public health emergencies."

GC on Article 11 should adopt the Guidelines on DI as a point of reference, possibly even draw from and elaborate the text, upon which to build further more generally. In any case, TCI suggests that there should be highest level of alignment between the Guidelines and GC on Article 11.

In particular, the GC on Article 11 should develop on the idea that "Institutionalization is a discriminatory practice against persons with disabilities. It involves de facto denial of the legal capacity of persons with disabilities, ... It constitutes detention and deprivation of liberty based on impairment, contrary to article 14. States parties should recognize institutionalization as a form of violence against persons with disabilities".

In particular, also, the GC on Article 11 should adopt the definition of 'institutions' as defined in the Guidelines.

The context of the Pandemic is unprecedented in the recent history of humankind and the Guidelines, issued by the CRPD committee, captures the full import of a human rights-based response to a disaster. While TCI appreciates that a GC on Article 11 is not only about de-institutionalization, and that for the stated purpose of de-institutionalization, the Guidelines already exists in the repertoire of UN Human Rights key documents. However, to have the text

¹⁵ CRPD/C/GC/6

blazoned into a General Comment will elevate the content of the Guidelines to the expected jurisprudence on Article 11.

b) "all necessary measures to ensure the protection and safety of persons with disabilities"

Communities must be supported by States parties to be inclusive, during normal times outside of emergencies and disasters. A culture of community inclusion must prevail in society in general, with comprehensive awareness programs on disability inclusion and disaster preparedness. This will ensure that during times of emergencies and disasters, no one is left behind, as communities would have been transformed to be inclusive already and community mobilizers during disasters and emergencies will be suitably prepared, and there will be no attitudinal barriers to address the needs of all persons with disabilities.

We emphasize that member states must ensure that all persons with disabilities have access to a continued life in the community, have access to all required support systems and services (general and specific), so that they can live a dignified and an independent life on an equal basis to others. In forecasting, preparation as well as in all rescue and restoration processes, before, during and after disasters, emergencies and humanitarian crises, key guidance on inclusion, independent living and the right to live in the community must be ensured.

States parties should provide a wide range of awareness activities in collaboration with OPDs, on the human rights of persons with disabilities, for all authorities, responders and actors at all levels of disaster response- preparedness, recovery and rebuilding. Community members will always be the first to respond, therefore, they should be given capacity building on disability inclusion, as a part of disaster drills and preparedness.

All stakeholders and communities must be transformed from the medical model to the more inclusive human rights model¹⁶, from institutionalization to the right to live in communities, from rehabilitation to inclusion and from treatment to support systems. The entry point for disaster preparedness must be wider, having the framing of inclusion for all persons with disabilities within the community.

Measures to ensure the protection and safety of persons with disabilities shall not mean creating aggregated housing, shelters, institutions, group homes, etc. As guided by the Guidelines on De-institutionalization, institutions increase the risks to life and liberty of persons with disabilities. Persons with psychosocial disabilities confined to such spaces must be evacuated and opportunities provided for resettlement in communities, on equal basis with others.

The process of de-institutionalization is a continuous process and must not only take place during emergency situations. De-institutionalization must figure in the national disaster management protocols. OPDs of persons with psychosocial disabilities should be involved during the process of designing, implementation and monitoring and evaluation of emergency response, relief and recovery

¹⁶ Bali Declaration (2018). Available at: <https://www.tci-global.org/bali-declaration/>

programs and policies^{17,18,19}. Budgets must be allocated for the closure Institutions and de-institutionalization must be done on priority basis, during humanitarian emergencies and disasters.

Legal barriers influence and shape social perceptions, attitudes, and barriers. Legal incapacity laws must be repealed on immediate basis, recognizing the extra-large threat that it poses to persons with psychosocial disabilities especially during humanitarian crises and disasters. State parties must ensure that all persons with psychosocial disabilities are recognized as persons before and under the law. In many parts of the world, informal guardianship is more prevalent than formal guardianship. The GC must recognize both formal and informal denial of legal capacity as requiring interventions by states parties. To address informal guardianship and incapacity, massive awareness campaigns must be funded by the governments to bring about attitudinal change in all stakeholders, on the autonomy, dignity, respect and will and preference, indeed, the personhood, of all persons with disabilities.

States must ensure that there is no gender and disability related discrimination during preparedness, response and recovery processes²⁰. All forms of violence against women and girls with psychosocial disabilities, LGBTQI community members found in disaster areas, in shelters and camps, must end.

State parties must ensure that persons with psychosocial disabilities and their organizations are involved and consulted keeping an intersectional approach in making all essential and peripheral services available. This must include and is not limited to prioritized access to disability-inclusive relief programs, health services, sexual and reproductive health services, habilitation and rehabilitation, personal assistance, housing, social security, skill development, employment and CRPD compliant community-based support systems and services.

For persons leaving institutions during a public health emergency, humanitarian emergency or disaster, a compensation package should be made available. They must be recognized as victims of the state (as per the DI Guidelines) and compensation and reparations process set in motion. Supports as needed to cover for the costs of having endured institutionalization must be included. Including supports to exercise legal capacity, personal assistance, and access to other community support networks, persons with psychosocial disabilities must have their social capital and support systems restored.

State parties must ensure that people with psychosocial disabilities and their organizations are actively consulted and involved in the consultation process. Such inclusive consultation process will guide humanitarian actors, INGOs, government and other stakeholders in identifying and eliminating the barriers which exclude persons with psychosocial disabilities during the emergency situations.

State parties must ensure that the ISAC guidelines are implemented at the national level and people with psychosocial disabilities are included during planning, implementation and monitoring processes.

¹⁷ CBM, IDA, PDF, & DFAT. (2022). *OUR LESSONS_ AN APPROACH TO DISABILITY-INCLUSIVE DISASTER RISK REDUCTION – BASED ON CONSULTATIONS WITH PEOPLE WITH DISABILITIES IN THE ASIA AND PACIFIC REGIONS*. Available at: <https://www.cbm.org.au/wp-content/uploads/2022/07/CBM-Inclusion-Advisory-Group-IG-Our-Lessons-report-May-2022.pdf>

¹⁸ UNDRR. (2022). *UNDRR STRATEGIC FRAMEWORK 2022 -2025*. Available at: <https://www.undrr.org/media/49267/download>

¹⁹ IDA, HI, & CBM. (2020). *Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD): Legal frameworks guiding inclusive humanitarian action and guidance for CRPD reporting*. https://www.internationaldisabilityalliance.org/sites/default/files/article-11-of-the-crpd-legal-frameworks-guiding-inclusive-humanitarian-action-reporting-guidance_final-version.pdf

²⁰ PANPPD, RLDP, TCI, ENUSP, CHRUSP, & WNUSP. (2020). *COVID-19 and persons with psychosocial disabilities*. Available at https://tci-global.org/wp-content/uploads/2022/05/COVID19-and-persons-with-psychosocial-disabilities-final_version.pdf

States must ensure that people with psychosocial disabilities have access to information in accessible and multiple formats through out a humanitarian program cycle. States must ensure that evacuation centers are accessible and inclusive of persons with psychosocial disabilities

- c) "persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters"

The Committee must consider and provide an expanded and comprehensive definition of 'disaster' and 'humanitarian emergency' as these are not defined in the text of the CRPD.

Not only whole countries should be seen as 'disaster prone' in international and national policies, but some geographic regions must be recognized, within countries as hazardous and prone to disasters of different kinds. Underrepresented disability constituencies, including persons with psychosocial disabilities are housed in disaster prone housing arrangements and areas. While locally experienced disasters may not have national scope of destruction, many closed-door institutions (Japan, India, SriLanka), aggregated housing facilities, community shelters, migrant shelters, makeshift accommodations, etc. face building related risks, building collapse, fire accidents, water logging and flooding, etc. where persons with psychosocial disabilities have been detained and have died *en masse*.

Such housing is found in urban areas of most world cities, as low-income areas, slums, etc. Especially during rainfall season or summers, such unstable, insecure housing is at heightened risk for disaster incidents. Such incidents should be considered under the rubric of Article 11, under urban development, building codes, schemes for housing, etc. and brought also under the purview of disaster management authorities and urban planners.

Due to climate change, in rural, mountainous, tribal and other remote areas where persons with disabilities may be residing, the younger populations move to city areas for study and work, leaving persons with disabilities and elderly behind, living in subsistence farms without any support²¹. Unseasonal rains, drought, unpredictable weather and water conditions, soil degradation, inflation of transport and other costs results in very meagre or no income for the effort put in, farm produce waste, debt and suicide risks. This is increasingly the scenario for rural areas in South Asia such as India, Pakistan, Nepal, etc. The impact of climate change decreases mobility, reduces resilience and employability of persons with disabilities, who get left behind in precarious environments, putting their life, wellbeing and liberty at risk.

The CRPD committee may consider the extended time it may take to transition from humanitarian emergencies, civil strife and areas coming out of militancy zones towards community development. Here communities and persons with disabilities are at risk for living substandard lives, being prone to external threats, long term inter-generational impoverishment, crime, substance use and other such features of living traumatized life in the margins. For example, in many parts of the world, the 'aura' of troops withdrawing, slow movements of army personnel through residential areas, presence of guns and army machinery, a trickling availability of relief measures, can go on for years due to political environments, unceasing day to day hostilities and negotiations, making the citizens, especially those disproportionately affected, to live in a situation of continued fear, terror and suspense about their future. Article 11 could specify that such 'transitioning' zones are *per se* a humanitarian emergencies. While humanitarian actions must be actively and comprehensively supported, it is also the political environment that must be addressed responsibly, with quick decision making, moral consideration of the good of all, remaining violence free, efforts to reconstruct all civic amenities and services; and early restoration of peace.

²¹ Shared by TCI member working on support systems in remote areas in the Asian region.

III. States obligations under article 11.

[Under this chapter, please kindly indicate what concrete obligations State parties and other actors have in the area of international law of your organization's expertise – IHL, environmental law, refugee law, disaster, e.t.c and the obligations under article 11 of the UNCRPD]

IV. Persons with disabilities disproportionately affected and experiencing particular disadvantages in situations of risks, such as:

[Under this chapter, please kindly provide narrative indicating which of the below groups, and for which reasons are at a particular disadvantage in situations of risks; are there other groups which are not mentioned which deserve particular attention?; what measures should be adopted under the UNCRPD to address their situation]

- a) Women with disabilities.
- b) Persons with disabilities in institutions.
- c) Children with disabilities.
- d) Older persons with disabilities.
- e) Internally displaced persons with disabilities, asylum-seeking and refugee persons with disabilities.

V. Interrelation with other articles of the Convention

[Please kindly develop narrative, from the field of your organization's expertise and the area of international law you work on, about the interrelation of article 11 with other provisions of the Convention, e.g. what States should do in situations of risks with regard to art 6 (women with disabilities), art.7 (children with disabilities, art 9 (accessibility), etc-

VI. Please indicate at least 5 issues, topics, comments, or recommendations your organization considers critical for the Committee to include in the draft general comment.
