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Transforming Communities for Inclusion (TCI)

CALL FOR INPUTS - Addressing the Impacts of Situations of Risk and Humanitarian Emergencies

Initial Draft – General Comment No. 10

Submitted to the:
Committee on the Rights of Persons with Disabilities Working Group in relation to its work on Article 11 of the Convention

Transforming Communities for Inclusion (TCI) is a global organization of persons with psychosocial disabilities and is represented by its 28 members in 21 countries. 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 define 'psychosocial disabilities' inclusively: persons who identify as with psychosocial disabilities, users and survivors of psychiatry, persons with intersectional, neurodivergent, 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.

Persons with disabilities, particularly those with psychosocial disabilities continue to living on the margins, and are most marginalized, and discriminated in society. Even after 20 years of CRPD we are confined discriminatory identities such as persons living with 'mental illnesses', people who are mental patients, mentally retarded, persons of 'unsound mind', 'mad' persons, etc. This poses intractable attitudinal, legal, social, economic, cultural and program barriers to access opportunities, take risks, make our own decisions, have our will and preference respected, and enjoy all fundamental human rights for living independently and on an equal basis with others[1].

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). We are stripped of our personhood and our right to identity, further exacerbated through guardianship and conservatorship laws. We are seen as 'Non-persons' who do not have any rights in society, including the right to access justice: We are the 'civil dead', and are not seen as persons 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 we are treated during humanitarian emergencies and disasters.

We highly appreciate the CRPD committee for developing a General Comment on Article 11 of the CRPD. The comments below target only the paragraphs where strong weight needs to be given to the perspective of persons with psychosocial disabilities, including the perspectives of those experiencing intersectional discrimination'. The shared comments draw on the Committee's Guidelines on deinstitutionalization, including in emergencies (CRPD/C/5); General Comment No. 1 (art. 12); the Guidelines on article 14; the report of the Special Rapporteur on torture on abuses in health-care settings (A/HRC/22/53); and grassroots evidence from our members.

Comments and proposals to different paragraphs and sections

Comment / proposal to paragraph 4

We are aware that during the humanitarian emergencies, in situations of risks, global crises, and conflicts a lot of focus is given to ensure availability of mental health and psychosocial support services. Moreover, there are massive investments that are made towards strengthening these MHPSS services by state and non-state actors and persons are forced to use these services in different settings. Also, parents of children, families, and community members push their family members or peers who are living with a psychosocial disability to access these services without asking their will and preferences. We understand the high importance of psychosocial support services during such emergencies but the committee should clearly mention that these services should be in compliance with the UN convention on the rights of persons with disabilities. Alongside, committee should also emphasize on the importance of community based support systems, which may be formal, voluntary or informal and should amend the draft's own wording accordingly. Any approach that promotes psychiatry or the medical model of psychosocial disability must be discontinued.

Proposed amendment and text: "The support systems or services to which persons with disabilities must have access in situations of risk can be formal, voluntary, informal or community-based, and should be grounded in free and informed consent of the person, the will

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

and preferences of the person, and are not denying the right to legal capacity of the person. The provided services should be developed within the disability-inclusion and community based inclusive-development frameworks. Approaches that promote psychiatry, segregation, institutionalization, discrimination or promote the medical model of disability including expansion of mental health services led by medical professionals, must be discontinued.

Basis: *CRPD/C/GC/1; CRPD/C/5.*

Comment / proposal to paragraph 6

The dignity paragraph rightly addresses ableism. However, we would like to suggest from TCI to mention specific forms of ableism against persons with psychosocial disabilities, like sanism, — these approaches in our communities tag persons with psychosocial disabilities as dangerous, curse of God, or incapable based on medical diagnosis. The committee should also recognize the pathologization experienced by gender-diverse persons with psychosocial disabilities. Persons with psychosocial disabilities from gender-diverse communities are historically classified as 'mental disorders' requiring cure or correction.

A possible proposed to the text: After "combatting ableism" add: "including its specific manifestation against persons with psychosocial disabilities, persons with intellectual disabilities, autistic persons and user-survivors of psychiatry, sometimes termed as sanism; beliefs of communities that psychosocial disability is a mental illness issue caused by curses, witchcrafts or supernatural forces or is a medical issue that can be cured with medications. These experiences and historical confinement of persons with psychosocial disabilities in Mental Health frameworks casts persons as dangerous, incapable or lacking agency,". This is further compounded for persons with psychosocial disabilities from gender diverse communities, whose identity and expression is pathologized as evidence of 'mental disorder', unsoundness of mind or lack of capacity, exposing gender-diverse persons with psychosocial disabilities to layered ableism and denying their agency both as persons with disabilities and as persons of diverse sexual orientation, gender identity and expression."

Comment / proposal to paragraph 7

We completely agree with the committees suggestions but we would like to suggest a few additions to this paragraph. For persons with psychosocial disabilities, the perception of communities and how we are identified in state constitutions and laws, that we are "mentally retarded", "Mental Patients" "dangerous" or of 'unsound mind' is precisely what drives our exclusion, informal guardianship and confinement, and our abandonment in emergencies. Under article 8 of the convention - Awareness-raising must therefore be a specific mention in the paragraph that plays a very key role in preparing communities before, during and after humanitarian emergencies so that communities and the first responders are already aware. We would also suggest deletion of word "stigma and replace with exclusion. Also, when we say specific needs of persons with disabilities, we want to share that given our historical confinement to medical frameworks and approaches and the frequent lack of information about rights-based options, persons with psychosocial disabilities may themselves express a wish for clinical or medical services and increases the risks of persons with psychosocial disabilities being institutionalized. Hence, we suggest mentioning CRPD compliant needs, recovery, and response for persons with psychosocial disabilities including youth, older persons and gender diverse persons.

Proposed text: Add: Poverty and discrimination reinforce one another. Any legal provisions that push persons with disabilities to the vicious cycles of poverty and discriminate persons with disabilities on the basis of their disability should be immediately repealed and reformed. State parties must ensure that all persons with disabilities, including persons with disabilities from under-represented groups have access to humanitarian assistance, employment, education, justice, voting and access to social protection on an equal basis to others.

Add another paragraph here on Article 8: "States parties must design and fund, and sustain awareness-raising programs before, during and after humanitarian emergencies — to transform community, family and institutional attitudes towards persons with disabilities. The state must ensure elimination of any assumptions against persons with disabilities that may deny their legal capacity. Such programs must be developed and delivered together with organizations of persons with disabilities, including organizations of young persons, older persons, women organizations and gender diverse communities, and must reach first responders, community leaders and faith and traditional-healing actors, and must promote the personhood, legal capacity, autonomy and community inclusion of persons with disabilities."

Basis: *CRPD, art. 8; CRPD/C/5, paras. 39–41.*

Comment / proposal to paragraph 8

We would like to suggest some iterations to the examples of reasonable accommodation in emergencies as persons with psychosocial disabilities rely on community support systems, and these support mechanisms can become even more complex, or specific during a situation of emergency. A person with disability may choose to seek support through a parent, community member, sibling, friend, peer supporter or a co-worker. The para mentions access to support personnel, but we suggest a clear mention of broader community support systems.

Proposed text: In the list of reasonable-accommodation measures can be added: "ensure access to community support systems and services for persons with disabilities during situations of humanitarian emergencies along with ensuring access to "low-stimulation, calm and quiet spaces; flexible rules regarding movement, food and sleep; privacy for other alternatives; access to chosen family members, peer supporters and other support persons; and arrangements that do not require public disclosure of a diagnosis or disability."

The community support systems and services are defined as follows:

Community support systems, and networks include the relationships that an individual develops with family members, friends, neighbors or other trusted persons who provide the support that a person requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community. Whereas community support services include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, the provision of assistive technology, support in securing housing and household help, and other community-based services.

Comment / proposal to paragraph 12

Due to our historical confinement in mental heath frameworks and systems, in many countries there are a very few OPDs of persons with psychosocial disabilities and in several countries OPDs don't even exist. There are several reasons for this (a) the shift from medical model to human

rights model is still evolving through efforts of different national, regional and global OPDs and self-advocates. (b) Due to legal incapacity frameworks, and guardianship issues many persons with psychosocial disabilities and groups who may want to register as formal OPDs are unable to do so. Hence, they are completely left out from the consultation processes. (c) In many countries we have observed that groups and networks who are transitioning to step into cross disability spaces for disability inclusive development are not welcomed by cross disability groups due to several reasons including lack of awareness, not sure how to support under-represented groups, many OPD groups are still transitioning from medical to human rights model, lack of resources, etc.

Moreover, organizations of persons with psychosocial disabilities, including older persons, young persons, and gender-diverse communities, mad persons, user-survivors of psychiatry, autistic groups, persons with intellectual disabilities remain under-resourced, excluded and our participation is often only tokenistic.

Proposed text: Add: "States parties must take specific measures to identify, resource, support and include organizations of persons with psychosocial disabilities, organizations of intellectual disabilities, including organizations of intersectional identities including youth, gender diverse and older persons, who are frequently less in numbers and are under-resourced. State parties must also ensure that all appropriate measures are put in place to support their meaningful participation in consultations, partnership development and inclusion in decision making processes for inclusive development for all.

Comment / proposal to paragraphs 13 and 14

We would like to emphasize to the committee that the para prohibits the institutionalization of persons with disabilities but it will also be important to name coercive practices (for .e.g. forced treatment, involuntary commitment, restraint and seclusion) because they are commonly experienced by persons with psychosocial disabilities, intellectual disabilities, user-survivors of psychiatry, mad persons, and autistic persons. The so-called 'conversion therapy' and other 'corrective' practices — including forced or coerced psychiatric and medical intervention, forced and over-medication, institutionalization, exorcism and 'deliverance' in prayer camps and faith-based settings, forced marriage and 'corrective' sexual violence — are frequently administered to gender-diverse persons with psychosocial disabilities in the name of treating a 'mental disorder'.

We also propose reframing the text regarding mental health services as these can be medical, and result as means to promote coercive practices against persons with disabilities. These coercive practices frequently begin in adolescence and young adulthood, when they are labelled with discriminatory identities, and young persons face involuntary commitment and forced treatment based on those so called medical diagnosis. Furthermore, gender diverse communities of persons with psychosocial disabilities experience 'conversion' and 'corrective' practices as a corrective measure and deny their right to identity, dignity, legal capacity and access to justice.

Proposed amendment and text: Amendment to paragraph 14: **replace text** "~~Protection in situations of risk continues to mean embracing and implementing the right of persons with disabilities to live and be included in the community, with access to community-based support services, including mental health services.~~" **with**…. "*Protection in situations of risk continues to mean identifying, addressing, eliminating barriers and intersectional discrimination against persons with disabilities, embracing and implementing the right of persons with disabilities to live*

independently and be included in the community, with access to rights based community support systems and services.

Add after paragraph 14 add: "The Committee specifies that, including in situations of risk, States parties must abolish and refrain from involuntary hospitalization and civil commitment, forced treatment and forced or over-medication, electroconvulsive treatment administered without free and informed consent, and chemical, mechanical and physical restraint and seclusion, all of which violate articles 12, 14, 15, 16 and 17 of the convention and should be recognized to torture, or inhumane degrade treatment. Supported decision-making arrangements must be maintained and strengthened during situations of emergencies, and must not be replaced by substituted decision-making or guardianship, whether formal or informal." States must ensure that Emergency psychosocial health team, crisis teams, police, and services for general health care, must not use distress, persons identity, unusual behavior, communication differences or the absence of a support person as grounds for involuntary hospitalization, detention or forced treatment.

Basis: *CRPD/C/GC/1; Guidelines on article 14; CRPD/C/5, para. 6; A/HRC/22/53 (Special Rapporteur on torture).*

Comment / proposal to paragraphs 17 and 18 (Intersectionality)

We strongly welcome the intersectional lens in paragraphs 17 and 18 and the recognition that risk is amplified for persons with disabilities on account of gender, sexual orientation or gender identity, age and other status. However, as a global organization of persons with psychosocial disabilities, we observe three gaps in the intersectionality section that should be addressed. First, the Committee's own table of contents lists "Older persons" as a subsection, yet no paragraph on older persons appears in the body of the draft. Second, the draft does not specifically address persons with disabilities from gender diverse communities and persons with disabilities from racialized communities. Third, the draft does not address youth and young persons with disabilities, who fall between the provisions on children and the general provisions for adults and are frequently left out of both. Persons with psychosocial disabilities within each of these groups — older persons, gender diverse persons, and youth — experience specific and compounded risks of psychiatrization, denial of legal capacity, forced treatment and institutionalization in situations of risk. We therefore urge the Committee to include dedicated paragraphs on each of the mentioned groups within Section III, and we propose text below.

Proposed text: Amend the illustrative list in paragraph 18 to read, remove cut text and add Italic: "— the present section provides examples of specific ~~protection~~ challenges and measures *to be* address*ed* them for women and girls, persons from racialized communities, children, young persons, older persons, persons with disabilities from gender diverse communities, Indigenous Persons, persons living in institutional settings and displaced persons with disabilities."

Basis: *CRPD, arts. 5 and 6; general comment No. 9; general comment No. 6.*

Comment / proposal to paragraphs 20 and 21

The paragraph must also highlight that women and girls with disabilities are also at risk of sexual and gender based violence in shelters and camps, especially women and girls with psychosocial disabilities, persons with psychosocial disabilities from gender diverse communities, young persons, intellectual disabilities, user survivors of psychiatry and autistic women and girls, depriving them of legal capacity, and they are disbelieved when they report for justice.

Proposed text: Rephrase para 20: “States must take targeted measures to identify, address, and eliminate heightened risk of sexual violence ~~protect~~ women and girls with disabilities face in situations of armed conflict, occupation of territories, disasters and humanitarian emergencies. States must take all measures to identify, address and eliminate sexual and gender-based violence in safe places, evacuation centers, refugee camps and shelters against women and girls with disabilities, gender diverse communities, youth, and older women with disabilities and guarantee their access to sexual and reproductive health services, voluntary and trauma informed recovery, and access justice through social or community justice systems. States must ensure that any support or reasonable accommodation required to facilitate persons with disabilities in accessing justice, is made available and provided to persons with disabilities.

Proposed text: Rephrase para 21 as in italic font:

States must recognize that women with disabilities living in institutions face a heightened risk of violence, exploitation, abuse, gender-based violence, harmful practices, and are more frequently denied the right to exercise their legal capacity than both men with disabilities and women without disabilities — resulting in denial of access to justice, choice and autonomy. States *must ensure to end disability-based discrimination and* integrate specific *CRPD compliant* ~~protective~~ measures for addressing these risks into the design and implementation of all emergency preparedness, response and recovery plans.

Proposal — new subsection under Section III (Intersectionality): Gender diverse communities of Persons with disabilities

Proposed text (new paragraph): “States parties must recognize that gender diverse communities of persons with disabilities face multiple and intersecting forms of discrimination in situations of risk, and are at heightened risk of forced treatment, “conversion” and “corrective” practices, denial of legal capacity and institutionalization. States parties must: (a) ensure that shelters, camps, evacuation centers, sanitation facilities and relief distribution are accessible and safe for persons with disabilities, including gender diverse communities are not denied access to any support, service or humanitarian assistance on the basis of sexual orientation. (b) prohibit and dismantle all systems, including in emergencies, that promote forced psychiatric intervention and “conversion” or “corrective” practices directed at a person’s sexual orientation, gender identity or disability; (c) ensure that access to humanitarian assistance, health care, and justice is not conditioned on gender markers, legal-gender recognition or the denial of legal capacity; and (d) identify, address, and eliminate sexual and gender-based violence against gender diverse persons with disabilities and guarantee access to recovery, support and justice on an equal basis with others.”

Basis: *CRPD, arts. 5, 12, 15, 16 and 25; general comment No. 9; Guidelines on deinstitutionalization, including in emergencies (CRPD/C/5).*

Comment / proposal — new subsection under Section III (Intersectionality): Young persons with disabilities

Proposed text (new paragraph): “States parties must adopt targeted measures to eliminate barriers and discrimination experienced by young persons with disabilities, who are frequently excluded from both child- and adult-focused support measures, in all situations of risks and emergencies. With particular regard to young persons with psychosocial disabilities, States parties must: (a) ensure continuity of inclusive education and of the community, peer and family support

systems on which young persons rely, and prevent their interruption during emergencies; (b) prohibit, including in emergencies, involuntary commitment, forced treatment and the imposition of guardianship or substituted decision-making on young persons, and maintain and strengthen supported decision-making instead; (c) eliminate all forms of exploitation, forced labor, trafficking and recruitment against young persons with disabilities; and (d) identify, resource and meaningfully involve youth-led and young persons' organizations of persons with disabilities, in emergency preparedness, response and recovery."

Basis: *CRPD, arts. 4(3), 12, 19 and 24; general comment No. 1; general comment No. 9.*

Comment / proposal — new subsection under Section III (Intersectionality): Older persons with disabilities

Proposed text (new paragraph): "States parties must recognize that older persons with disabilities, face intersecting ageism and disability-based discrimination that heighten their risk of institutionalization, denial of legal capacity, exclusion to access services, guardianship, over-medication and abandonment in situations of risk. States parties must: (a) ensure the immediate identification, evacuation and community living measures for older persons with disabilities detained in nursing homes, aged-care facilities, dementia wards and other institutions, and investigate deaths resulting from their abandonment or non-evacuation as violations of the right to life; (b) refrain from institutionalizing older persons with disabilities as a condition of protection or care, and refrain from rebuilding or repopulating aged-care institutions after emergencies; (c) prohibit, including in emergencies, forced treatment, over-medication, and chemical, mechanical and physical restraint of older persons with disabilities; (d) ensure the availability and continuity of community-based support systems, supported decision-making and peer support, access to mainstream services that enable older persons with disabilities to live and be included in the community on an equal basis with other; and (d) ensure that older persons with disabilities have access to different social protection schemes, settlement packages, housing support, universal health coverage, reasonable accommodation, assistive devices required to mobilize independently in communities."

Basis: *CRPD, arts. 12, 16, 19 and 25; Guidelines on deinstitutionalization, including in emergencies (CRPD/C/5); general comment No. 9.*

Comment/proposal to paragraphs 23-27

The Committee recognized the importance of applying the best interest of the child to all measures taken to protect children with disabilities; however, it is key for the guidelines to explicitly recognize the principle of the evolving autonomy of children with disabilities. Therefore, to recommend States to implement all measures to include the active participation of children with disabilities in all decisions that affect them.

Proposed text: States Parties must recognize and apply the principle of the evolving autonomy of children with disabilities in all measures relating to disaster risk reduction, humanitarian emergencies, and situations of risk. They must ensure that children with disabilities are provided with accessible information, appropriate support, and meaningful opportunities to participate in decisions affecting them. The views, will, and preferences of children with disabilities must be respected and given due weight according to their age and maturity, in accordance with the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child.

Comment / proposal to paragraph 27:

The guidelines recommend States to remove all barriers preventing displaced children from accessing both formal and non-formal education. However, it is key that States not only remove the barriers but create specific actions to promote and ensure that all children with disabilities who have been displaced receive education.

Comment / proposal to paragraphs 28-30

In many countries, there is limited understanding of the lived experiences of Indigenous persons with disabilities and of the diverse ways Indigenous communities understand disability. This gap may significantly affect the design and implementation of disaster risk reduction, preparedness, humanitarian response, and recovery measures, increasing the risk of exclusion and discrimination. States Parties should therefore ensure that all actions relating to situations of risk and humanitarian emergencies incorporate both disability-inclusive and intercultural approaches, developed in partnership with Indigenous Peoples and Indigenous persons with disabilities.

Proposed text: States Parties must ensure that collaboration with Indigenous Peoples in disaster risk reduction, humanitarian response, and recovery respects their right to self-governance, self-determination, and traditional governance systems. Within these collaborative processes, States must promote the rights of Indigenous persons with disabilities through culturally appropriate and intercultural approaches, ensuring their meaningful participation and addressing the multiple and intersecting forms of discrimination they may experience.

Comment / proposal to paragraph 31

We welcome the twin-track approach and that the process of deinstitutionalization and transition into community living with supports should be pursued together with processes of ensuring protection for persons with disabilities still living in institutions. However we suggest it should (i) name the full range of settings in which persons with disabilities are always on the risk of being detained; (ii) enumerate the harms of institutionalization; (iii) require the immediate halt of any approach that promotes psychiatry or the medical model; and (iv) require that independent monitoring continue during emergencies. These should be clearly articulated by the GC so that the states and local governments are clear on what could be the possible types of institutions, or harms they create are against human rights of persons with disabilities, and that these institutions should be dismantled immediately, with proper monitoring mechanisms.

Proposed text: Add: “Institutions in which persons with disabilities are detained can include and are not limited to psychiatric hospitals, social-care institutions, nursing homes and secure dementia wards, de-addiction and rehabilitation centres, half-way homes, group homes, sheltered or protected living settings, forensic and transit homes, prayer camps and faith-based and traditional-healing settings, as well as informal confinement, chaining and shackling in homes. Social care institutions and communities. In all such forms, institutionalization exposes persons with disabilities to violence, neglect, abuse, ill-treatment and torture; to chemical, mechanical and physical restraint and seclusion; to forced treatment, forced and over-medication, and electroconvulsive treatment without free and informed consent; to the denial of legal capacity; and to isolation and segregation. In the situation of disasters persons with disabilities who are institutionalized experience abandonment and deaths, being neither evacuated nor rescued.

States parties must recognize institutionalization as a form of violence; immediately halt any approach that promotes psychiatry or the medical model of disability; adopt a moratorium on new admissions and on the construction, refurbishment or renovation of institutions; ensure the immediate identification and evacuation of those detained; refrain from rebuilding or repopulating institutions after emergencies; prohibit forced treatment, restraint and seclusion of those who remain pending release; and ensure that independent monitoring of institutions continues, and is not suspended, during emergencies, with the participation of survivors of institutionalization."

Basis: *CRPD/C/5, paras. 2, 6, 8, 13, 107–113, 136–137.*

Proposed text Para 35:

Add after the first sentence: "States parties must take measures to prevent and address all kinds of discrimination and barriers faced by displaced persons with disabilities. States must ensure that the perceptions against displaced persons with disabilities that they constitute an undue burden on public resources or services or are less deserving of assistance is addressed. Such measures must address intersecting forms of discrimination and ensure that displaced persons with disabilities, including persons with psychosocial disabilities, are not excluded from humanitarian assistance, social protection, community-based support or other services on the basis of their disability.

Proposal / comment to paragraph 36

Comment: We welcome the Committee's recognition that situations of risk heighten threats to the lives of persons with disabilities and that violations of the right to life may arise in a range of situations, including during institutionalization. We recommend strengthening this paragraph to explicitly address the heightened risk to the lives of persons with psychosocial disabilities who are detained in institutions or subjected to informal confinement in homes and other settings in the name of "protection and safety". Persons who are institutionalized or confined may be unable to evacuate independently, and have repeatedly been left behind or abandoned during disasters, fires, floods and public health emergencies. The Committee should make clear that deaths resulting from failure to evacuate, abandonment or the absence of appropriate emergency measures in such settings must be treated as potential violations of the right to life and must be subject to effective investigation and accountability.

The Committee should also clarify that investment in, construction, renovation or refurbishment of institutions cannot be considered a measure to protect the right to life or improve the quality of life of persons with disabilities. The protection of the right to life requires States parties to ensure access to inclusive, community-based supports and services, social protection, adequate housing and settlement support, measures addressing disability-related extra costs, employment and livelihood opportunities, and quality general healthcare, including during emergencies. These measures are essential to reducing the conditions that place persons with disabilities at heightened risk and to ensuring that they can live safely and with dignity in the community.

Proposed text: Add in the paragraph that "States must take appropriate measures to be taken to ensure that persons with psychosocial disabilities detained in institutions or subjected to informal confinement are not left to die in disasters, fires, floods and public health emergencies, and investigate, as violations of the right to life, deaths resulting from their abandonment or non-evacuation. Building, renovating refurbishing, and promoting new, private or public institutions should not be considered as a "support for persons with disabilities" in the name of

quality life. Sates must ensure that persons with disabilities have access to all range of community based supports, and services; access to social protection mechanisms, including housing, settlement packages, in-kind support, disability related extra cost; ensure access to employment and livelihoods of persons with disabilities; and access to quality general health care during emergencies.

Basis: *CRPD/C/5, paras. 107–113.*

Comment / proposal to paragraph 37

Sub-paragraph (c) recognizes a heightened duty of care by state parties. Our movement of persons with psychosocial disabilities has been historically confined in homes (informally), social care institutions, and several other forms of institutional settings. For persons with disabilities in particular, institutionalization and coercive systems have historically been justified in the name of care, treatment and protection, while often resulting in serious violations of autonomy, legal capacity, dignity and other human rights. States must ensure that providing care should not be responsibility of states, or institutional services, and should not be controlled by states or institutional authorities. Care is fundamentally rooted in human connections, family and friends relationships, mutuality and solidarity of persons living in communities. The State's responsibility should therefore be understood as ensuring that persons with disabilities can live and participate in their communities on an equal basis with others, by ensuring persons with disabilities access to community support systems and services. The focus of state should be on preventing deprivation of liberty and institutionalization, while ensuring appropriate safeguards for those currently deprived of liberty and states must invest in community-based support systems that enable all persons with disabilities to live independently and be included in the community.

Proposed rephrased text: The State has a heightened obligation to respect and support the lives and bodily integrity of persons with disabilities who are deprived of their liberty, including those in institutions, prisons and other settings. States must ensure that any form of protection or care that segregate persons with disabilities from mainstream communities is not promoted or implemented, persons with disabilities should live and participate in their communities on an equal basis with others, through access to accessible, rights based support systems and services that respect autonomy, legal capacity, dignity and choice of the person. State parties must ensure to promote community based inclusive development programs, and organize specialized programs on community development, where care is recognized a human relationship, a support system, a connection between humans, mutuality and solidarity between people living inside a community. State must ensure that care is not recognized or promoted as a service in communities and ensure that no person is deprived of liberty in the name of care or protection.

Also add in the section “refrain, including in emergencies, from forced psychiatric intervention, forced and over-medication, electroconvulsive treatment administered without free and informed consent, and chemical, mechanical and physical restraint and seclusion, which violate articles 15 and 16 and should be recognized as torture or ill-treatment.”

Comment / proposal to paragraph 38

The section (a) only limits to IASC guidelines to identify the needs of persons with disabilities, whereas we propose keeping it broad, and go beyond the IASC guidelines where persons with disabilities can also be consulted regarding their needs. Since this section highlights about adequate standards of living for persons with disabilities, it is critically important to highlight on

access to CRPD compliant community support systems, and services, for our movement they play a critical role to mobilize in communities independently, and access mainstream services.

Proposed text: rephrase (a) as: Implement a wide range of measures to address the needs of persons with disabilities, as reflected in the IASC Guidelines and identified through inclusive and participatory consultation mechanisms, ensuring that all needs required to maintain an adequate standard of living during situations of humanitarian emergencies are identified, addressed and provided.

Also add: "States parties must ensure that persons with disabilities are not deprived of their legal capacity, and are not excluded from food, water, cash transfers, in-kind relief and social protection on the basis of their disability or legal status, and must guarantee that they are not last in line, nor left to starve, in camps, droughts and famines." Persons with disabilities must have access to community support systems to enable them to access available services.

Proposal to paragraph 39

Proposed text: Add as measures: "ensure that persons with disabilities have access to general and physical health care including medicines, prescriptions, pharmacies, medical consultations, and home nursing on an equal basis with others and are not denied it through diagnostic overshadowing; no person should be forced to take medication without their choice; states must ensure availability of CRPD compliant psychosocial support services, personal assistance, crises support, peer support, delivered within a disability-inclusion rather than a medical framework; prohibit involuntary treatment and detention in the name of health care and rehabilitation; and ensure that triage and rationing protocols do not deprioritize persons on the basis of any disability."

Proposed rephrase to (b) remove the cut and replace with Italic: Ensure the development of support services that are ~~person-centered, age- and gender-sensitive and culturally appropriate… person-centred, age-~~ *gender-and sexual orientation-sensitive and culturally appropriate,* bearing in mind the particular importance of the World Health Organization's Priority Assistive Products List in situations of risk and emergencies; and

Comment / proposal to paragraph 42

We strongly welcome sub-paragraph (b), which prohibits making institutionalization a condition of protection such as evacuation. In many instances, persons with disabilities are on a risk to be re-institutionalized after emergency situations. This approach also diverge the humanitarian and reconstruction funds to renovate institutions.

Proposed text: Add: "*"Loss of housing, family support, community services or local infrastructure must not result in placement of persons with disabilities in psychiatric hospitals, social-care institutions, group living arrangements or other settings not freely chosen by the person. States must ensure persons with disabilities have access to CRPD compliant recovery programs. Reconstruction funding must prioritize accessible housing, development of inclusive communities, individualized support systems, peer support, supported decision-making and restoration of community networks."*

Basis: *CRPD/C/5, paras. 108, 113.*

Comment / proposal to paragraph 42

Rephrase the para as follows: (a) Support protection mechanisms, including governmental oversight bodies, the Global Protection Cluster and national human rights institutions, where these are fully in compliance with the UNCRPD to establish a specific area of responsibility or units that work to address the needs of persons with disabilities during situations of risk as a specific group, but also within the broader context and as a part of the general population.

Comment / proposal to paragraph 45

We welcome sub-paragraph (b) on discontinuing segregated and medicalized services. For the clarity of state parties and other non-state actors, it will be good to also mention the possible specific private and informal actors who may detain persons with disabilities.

Proposed text: Add: "States parties must regulate and, discontinue services that are segregated, medicalized or not based on the will and preferences of persons with disabilities on the basis that they seriously enhance risks for persons with disabilities. These can include and are not limited to private psychiatric facilities, de-addiction and rehabilitation centers, group homes, special education centers, care homes, social care institutions, disability specific residential institutions, nursing homes, etc.

Comment / proposal to paragraph 46

As persons with psychosocial disabilities we have observed that in many global spaces and several training modules are developed under the framework or with a specific focus on mental health and not on inclusion. Hence it should be stated in the section that states promote capacity building modules that are in compliance with CRPD, include all persons with disabilities and promote disability inclusive development.

Proposed text: Add: "States parties must ensure monitoring mechanisms through organizations of Persons with Disabilities to ensure that any training or capacity building led by (state or non-state) actors addresses intersectional discrimination and is in full compliance with the UNCRPD, and promotes disability inclusive development.

Comment / proposal to paragraph 47

For full inclusion of persons with psychosocial disabilities in situations of risk depends on the availability of CRPD-compliant support systems — both formal (personal assistance, supported decision-making, individualized funding, voluntary community-based crisis support) and informal (peer support, self-help and mutual-aid groups, family and community networks). These are precisely what is lost during emergencies and lockdowns. There is also a requirement here to explicitly mention the De-institutionalization guidelines as they also highlight on service provision during emergencies in several sections. Also we would like to propose discontinuation of the term community based rehabilitation, and only use community based inclusive development. Hence we would like to propose following changes to the text.

Proposed text: Add: (a) States must apply the Inter-Agency Standing Committee's Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action and, Guidelines on deinstitutionalization, including in emergencies to ensure non-discrimination in situations of risk and humanitarian emergencies across all programs and actions;

(c) Link disability-related support systems and services, provided in some contexts under the framework of community-based inclusive development, with existing services and networks in the community and avoid segregation and isolation of persons with disabilities;

Basis: *CRPD/C/GC/5; CRPD/C/5.*

Proposal to paragraph 48

Add: "State parties should establish national CRPD implementation and coordination mechanisms with meaningful participation of organizations of persons with psychosocial disabilities to oversee legal reform, emergency preparedness, disability-inclusive humanitarian action, monitoring and accountability to ensure that no person with disability is left behind during situations of risk".

Comment / proposal to paragraph 50

We want to highlight that the existing data collection tools for persons with disabilities are standardized on a functional approach to disability, and present that there are functional limitations in a "person" instead of the environment – this approach is medical model and is not incompliance with the CRPD. Hence we suggest that all data collection tools must be inclusive, and based on the barriers they face for participating in community life on an equal basis to others. Data must also be disaggregated in ways that make youth and young persons, older persons, and gender diverse persons with psychosocial disabilities visible, who are otherwise rendered invisible in emergency data.

Proposed text: Add to 50 (a) Ensure that any protection measures put in place by state are rights-based, in compliance with the UNCRPD, do not promote segregation or institutionalization, and are founded on an understanding of the specific requirements and priorities of persons with disabilities during a crisis. Applying this framework means: (i) using rights based data collection tools for identifying the population of persons with disabilities; (ii) analyzing the risks that persons with disabilities face and the factors that contribute to those risks; (iii) identifying barriers that impede persons with disabilities from accessing assistance during a crisis; and (iv) promoting partnerships between (non-state and State) actors, organizations of persons with disabilities, national disaster management authorities, humanitarian organizations, to collective eliminate the identified barriers and promote disability inclusive preparedness, response and recovery; (v) Establish national CRPD implementation and coordination mechanisms with meaningful participation of organizations of persons with psychosocial disabilities to oversee legal reform, emergency preparedness, disability-inclusive humanitarian action, monitoring and accountability to ensure that no person with disability is left behind during situations of risk. (vi) Data collection must be voluntary wherever possible, purpose-limited, secure and transparent. Persons with disabilities must be informed about who will use the data and for what purpose. Data concerning disability identities, and required support needs must not be shared for policing, immigration control, involuntary hospitalization, guardianship, institutionalization or other discriminatory purposes."

Basis: *CRPD/C/5, para. 114; 'Our Lessons' (2022).*