TCI Submission for WHO's Consultation on Global Standards for Long-Term Care

Supportive submission for Liberation (UK), member organization from the UK

About TCI: Transforming Communities for Inclusion (TCI Global) is a post CRPD inclusion movement and a global, membership-based organization of persons with psychosocial disabilities (OPD) with 28 members from 21 countries. TCI forecasts a future in which all human rights and full freedoms of persons with psychosocial disabilities are realized and we are guided by the extraordinary vision of the CRPD.[1]

We are sending this submission, in support of our full member, Liberation's (UK) submission.

Liberation is led by persons with psychosocial disabilities and has both individual and organizational membership. Its remit is adults of all ages who have psychosocial disabilities, and is well represented by older members, too. Liberation's submission brings credible and legitimate concerns with WHO's 'Global Standards for Long Term Care' document. We are also taking this opportunity to highlight some additional feedback, and we truly hope that subsequent draft of this document will pay particular attention to older persons with psychosocial disabilities, align itself with the provisions of the CRPD, and be open for further public consultations.

TCI appreciated the substantial rights language throughout the working draft, and the consideration of community based and home-based support options for older persons. However, we are concerned that the wider operational framework still allows professionals and families to determine when autonomy can be overridden and when institutional placement becomes appropriate. This is completely contrary to the provisions and principles of Article 12 and 19 of the UNCRPD, under which persons with psychosocial disabilities retain legal capacity on an equal basis to others and have the right to choose where to live, with whom to live, and are not obliged to live in any particular living arrangement.

As Liberation has noted at the outset of its submission, older persons have been portrayed in passive terms, perceived deficiencies, as care receivers or vulnerable. TCI rejects this paternalistic framing and reaffirms the suggestion of aligning with a CRPD compliant and right holders language so that all related services, supports, assistance are designed and delivered under the direction of older persons themselves, respecting their will and preferences and enabling them to exercise choice and control over their lives. Ironically, in the section where long term facilities are being called as empowering environments, it is stated that '*residents are permitted privacy*' which further reinforces that privacy is an aspect that is granted by a

[1] https://tci-global.org/

provider or anybody in the hierarchy. TCI also agrees that the title and the text of the document should focus on 'long term support' rather than 'long term care' as support and assistance are in line with the CRPD, and recognizes persons with psychosocial disabilities, needing supports for living in the community and being included, on an equal basis with others, rather than merely as care receivers.

TCI also strongly endorses Liberation's pointed concerns that the document puts forward a reform-oriented approach rather than a complete transformation approach and lacks a focus on ending all forms of institutionalization and substituted decision making. In line with the UN Guidelines on Deinstitutionalization, all forms of institutions in the name of care or living arrangements for children or older persons should be closed, rather than reforming them or downsizing them.

The document states that long term facilities are stigmatized in many countries and are portrayed as dehumanizing spaces where individuals do not have full freedom or decision-making authorities. As a movement of survivors of institutionalization, many of us and our peers have endured the human rights violations in these spaces and continue doing so.[2,3,4] Hence, we would caution that legitimate criticism of institutional facilities should not be reframed as merely 'stigma'. We affirm Liberation's call to align the working draft with the UN CRPD, and the UN Guidelines on Deinstitutionalization, including in Emergencies[5]. Additionally, in the CRPD Committee's recently adopted Guidelines on Disability Based Violence, institutionalization has been called a form of disability-based violence, and it has been documented that 'systematic neglect, coercion and dehumanization for persons with disabilities' is enabled by the practice of institutionalization.[6]

TCI also appreciates that the working draft mentions respecting and upholding older person's right to autonomy and legal capacity. However, as highlighted by Liberation, TCI reiterates concerns around the 'exception' based framing in the same document. Both these ideas in the same document represent a conflicting picture and makes space for substituted decision making, overriding will and preferences of older persons with disabilities. Although the document correctly acknowledges that often, others take decisions on behalf of older persons, but the inclusion of 'mental capacity' 'best interests' 'lacking capacity' is in contradiction to the earlier statement. In another instance, 'lacking capacity' has also been used to justify decisions by 'nominated others'. However, the bigger question is who nominates these representatives and can older persons reject or change these

[2] Prax, C. (2024). *Ending institutionalization (including involuntary detention in psychiatric hospitals and forced treatment)*. https://whatweneed.in/wp-content/uploads/2025/01/Blog-from-Cheryl-Prax.pdf
[3] TCI. (2022). *House of Horrors, Tale of terror: Sadly, nothing new here An opinion piece on the BBC Panorama undercover investigation of the Edenfield Mental Health Care unit, UK*. https://whatweneed.tci-global.org/wp-content/uploads/2023/01/WhatWENeed-submission_TCI_Final.pdf
[4] UN CRPD Committee. (2026). *Report on the investigation into Mexico conducted pursuant to Article 6 of the Optional Protocol to the Convention*. https://drive.google.com/file/d/1g3jsMWYYZ6-S2tdfyktF-BhHZlreuRSd/view
[5] CRPD/C/5. https://digitallibrary.un.org/record/3990185?ln=en&v=pdf#files
[6] CRPD/C/8. https://www.ohchr.org/en/documents/thematic-reports/crpdc8-guidelines-identifying-and-addressing-disability-based-violence

representatives. General Comment 1 of the CRPD also promotes the abolition of substituted decision making and its replacement with the supported decision making.

It should be clearly noted that for older persons with psychosocial disabilities, the identity of being persons with mental illness or persons with unsound mind is the basis on which decision making authority and legal capacity is denied.[7,8] Article 14 of the CRPD affirms that a person with a disability cannot be deprived of liberty, cannot be detained or treated in segregated settings on the basis of their disability or assumptions of unsoundness of mind, etc. The reform-oriented approach in the working document could also be misconstrued to suggest that amending or reforming of mental health legislations, that have been detrimental to persons with psychosocial disabilities, can be the way forward. These legislations have enhanced State and medical lobbies power over personal liberty of persons with psychosocial disabilities by acting as a legal filter to catch the 'violent lunatic'. [9] The working document should be cautious not to leave room for this interpretation and reinforce the human rights framing it has already presented in certain places. The working draft does explain in detail about the need for enabling home-based care respecting persons' autonomy and choice. However, the capacity-based exceptions in the document can undermine these safeguards.

Adding to this, the section on freedom from restraint and coercion clearly acknowledges that 'use of restraints restricts liberty and violates fundamental rights to autonomy, dignity, and freedom of movement'. But, 'exceptional circumstances' 'immediate risk of serious harm' again end up reinforcing the stereotypes of being 'violent' attached with persons with psychosocial disabilities. It opens space for retaining coercion within the system, instead of questioning the practice itself. Restraint, seclusion and other coercive practices have been recognized by the CRPD Committee as forms of ill-treatment contrary to Articles 14 and 15, for which no justification is permissible. Further, as Liberation highlighted, the working draft has no acknowledgement of involuntary hospitalization and involuntary treatment of persons with psychosocial disabilities as breach of human rights.

The working draft elaborates on establishing a durable financial framework for long term care, but does not mention time bound deinstitutionalization, establishing routes to exit, and redirecting financing from institutional care towards community living models. This is in divergence from the UN Guidelines on Deinstitutionalization, which specifically calls for moving resources away from institutions or facilities towards independent living and community support.

---

[7] *Statement of Expert Testimony on the topic of Legal Capacity and Guardianship of persons with disabilities, before the Hon. Constitutional Court of Indonesia.*, Hon. Constitutional Court of Indonesia. (2023). https://tci-global.org/wp-content/uploads/2024/02/Submission-Indonesia-Constitutional-Court-Expert-Testimony-TCI.pdf

[8] TCI. (2023). *Paper on Intergenerational Solidarity and Inclusion of Older persons with Psychosocial Disabilities*. https://tci-global.org/wp-content/uploads/2024/02/Paper-on-Intergenerational-Solidarity-and-Inclusion-of-Older-persons-with-Psychosocial-Disabilities.pdf

[9] 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

As Liberation has remarked, older persons with psychosocial disabilities remain explicitly absent for this working draft. For this constituency, ageism intersects with discrimination based on psychosocial disability.[10] In the context of older persons with psychosocial disabilities who have been living with psychiatric labels, all possible assumptions of incapacity, treated as a burden, family decision and subjected to coercion disguised as treatment or 'care', will determine where and with whom they end up living. When we name this constituency clearly, it makes it possible to challenge the discriminatory underlying mechanisms and to ensure access to support that respects their will and preferences and enables community inclusion. Moreover, little to no attention has been given to people ageing after decades of psychiatric institutionalization, forced treatments, forced medications, being subjected to ECT, separation from family or community. Their experiences and requirements for leaving institutions, rebuilding relationships and exercising control over their lives must be addressed.

TCI also supports Liberation's recommendation for greater emphasis on housing and mainstream services, and community resources needed for independent living and community inclusion.[11] As these areas are strengthened, older persons with psychosocial disabilities must be explicitly recognized, alongside other intersecting identities and experiences of discrimination. Their omission risks leaving specific barriers and support requirements unaddressed in policies concerning housing, income support, social protection, well-being and peer support.

We support the provisions of healthcare, income support, respite care for unpaid carers. However, we also express concerns that older persons with disabilities have been dominantly represented at the side of care receiving. We confirm that many older persons with psychosocial disabilities, including women with psychosocial disabilities are also care givers in their household and communities, and a sole focus on their 'care needs' does not do justice to their contributions.[12] The working draft should explicitly recognize these overlapping roles and ensure that they can access support both as persons with disabilities and as caregivers.

To conclude, older persons and their representative organizations must lead these processes. The support of allies such as civil society groups, service providers are always welcome but must never replace leadership. Reiterating Liberation's position, if the draft is to truly reflect the needs and priorities of older persons, it must be made available in accessible formats, multiple ways of sharing feedback, an extended deadline and further rounds of consultations

[10] TCI. (2025). *Report on the right to social protection and the right to work of older persons: Submission to the Independent Expert on the enjoyment of all human rights by older persons*. https://tci-global.org/wp-content/uploads/2025/03/Call-for-Inputs-Older-Persons-and-Right-to-Social-Protection-Work.pdf

[11] TCI. (2025). *Report on the right to social protection and the right to work of older persons: Submission to the Independent Expert on the enjoyment of all human rights by older persons*. https://tci-global.org/wp-content/uploads/2025/03/Call-for-Inputs-Older-Persons-and-Right-to-Social-Protection-Work.pdf

[12] TCI Global. (2024). *TCI Global's written submission to Working Group on discrimination against women and girls on Gendered dimensions of care and support systems*. https://tci-global.org/wp-content/uploads/2024/12/TCI-Globals-written-submission-_Working-Group-on-discrimination-against-women-and-girls-Gendered-dimensions-of-care-and-support-systems-.pdf

on subsequent drafts. The leadership of older persons, including older persons with psychosocial disabilities must be made central at every stage including setting priorities, developing standards to implementation, monitoring and evaluation of services. Participation must extend beyond invitations to review or comment, ensuring that older persons have full decision-making authority over the standards, services and supports that affect their lives.