TCI Global's written submission

Working Group on discrimination against women and girls
Gendered dimensions of care and support systems

About TCI: Transforming Communities for Inclusion (TCI)[1] is a global Organization of Persons with Psychosocial Disabilities (an OPD) and post-CRPD movement of persons with psychosocial disabilities and its cross-disability supporters. It is a membership-based organization, with a presence in over 50+ countries spread across various sub regions of South Asia, SEA, Pacific, East Asia, MENA region countries, East Africa, West Africa and Latin America. TCI also has a small set of members from Europe, USA, Australia and Canada. Our identity of person with psychosocial disabilities is derived from the CRPD description of the disability and is inclusive of persons who identify as 'users and survivors of psychiatry, 'mad' persons', persons who have been targeted as 'of unsound mind', autistic persons, persons with intersectional and neurodiverse identities, including persons with psychosocial disabilities. Recently, *TCI Women*, a platform of women with psychosocial disabilities was launched during the TCI plenary conference in November 2024.

TCI warmly welcomes the initiative of the Working Group on discrimination against women and girls to call for inputs on gendered dimensions of care and support systems. It is a crucial topic for women, and we take this opportunity to provide our inputs as women with psychosocial disabilities. We congratulate the Working Group for having such a broad vision to realize and address the gendered aspects of the current discourse. We also appreciate the range of questions in the questionnaire that cover multiple aspects of this topic.

Missing piece: Crucial intersection of disability and gender

We acknowledge the efforts of the Working Group to examine the care and support systems through a gendered lens. It is much needed. However, we would like to request the Group to also prioritize the intersection of disability and gender in its analysis to enable a comprehensive understanding of the nuances of care and support systems. Women with disabilities, especially women with psychosocial disabilities face compounded layers of oppression and discrimination; as women, as women with disabilities and as women with psychosocial disabilities. Negative stereotypes such as being incapable to take own decisions, inability to think, to know what is right or wrong are deeply embedded in sociocultural norms and reinforced by discriminatory legal

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

frameworks. These biases and assumptions often result in one of our identities being erased or prioritized, further diminishing our agency, autonomy and visibility. Even within broader movements advocating for other disabilities or women rights, women with psychosocial disabilities remain at the periphery. In our experience, our disability aspect maybe acknowledged but the gendered dimension of these issues is frequently overlooked, making us reflect on Sojouner Truth's quote '*ain't I a woman*?'. This reflects a disturbing dichotomy where intersectionality is acknowledged in theory but not practiced. Recognizing this gap and addressing it is essential to ensure that experiences and realities of women with psychosocial disabilities are truly and meaningfully included within these broader debates.

Support, NOT care

Traditional care models and the associated care policies have followed the narrow medical model perpetuating decades of harm, violence and oppression on person with disabilities, especially women with psychosocial disabilities[2]. The act of merely assigning a label or a diagnosis have led to women with psychosocial disabilities being violently uprooted from their homes, families, communities and forcefully put into institutions and subjected to coercive practices. This has been done and continues to be done under the guise of 'care'. These models frequently portray women with psychosocial disabilities as passive recipients and in need of care and protection rather than as right holders. Persons with psychosocial disabilities have been subjected historically to all forms of violence, including custodial violence, from 'care providers'. The three decades old philosophical debate on ethics of rights versus ethics of care was tackled by disability movement, women movement and eminent philosophers, particularly Martha Nussbaum and brought forward ideas that cut through the polarization between care and rights.[3] The ushering of disability rights and the CRPD marked a deliberate and a strong rejection of traditional care models, embracing instead the right to support, accommodations and assistance. This was necessitated by the dismal failure of care systems and policies. The CRPD includes complete guidance on 'supports' and UN Guidelines on Deinstitutionalization, including in emergencies provides exhaustive inventories on policy and legal actions to be taken, to build up circles of care, support systems and services, as well as enabling persons with disabilities to access mainstream services on equal basis with others[4].

[2] *Human Rights Watch Submission in Relation to Argentina's Request for an Advisory Opinion by the Inter-American Court of Human Rights on the Right to Care | Human Rights Watch*. (2023, November 28). https://www.hrw.org/news/2023/11/28/human-rights-watch-submission-relation-argentinas-request-advisory-opinion-inter
[3] TCI. (2023). *'Support' as 'Care': A/HRC/52/52 (advanced unedited version) report from the OHCHR: A response from TCI*. https://tci-global.org/wp-content/uploads/2023/06/Final-Support-versus-care-TCI-response-to-A-HRC-52-52.pdf
[4] TCI. (2023). *'Support' as 'Care': A/HRC/52/52 (advanced unedited version) report from the OHCHR: A response from TCI*. https://tci-global.org/wp-content/uploads/2023/06/Final-Support-versus-care-TCI-response-to-A-HRC-52-52.pdf

All pervasive systemic violence – a harsh reality in the lives of women with psychosocial disabilities

Despite 17 years since the CRPD, women with psychosocial disabilities continue to be deprived of their legal capacity by laws, regulations and practices, rendering them legally non-existent. With multiple layers of identity viz gender, disability, indigenous identity, age, they are at a greater risk of having their legal capacity being taken away. When incapacity provisions applied in law gets entrenched into the daily lives of women with psychosocial disabilities, their personhood is not recognized nor validated.[5] They are stripped of their legal capacity, which is the right to have all other rights[6], and constitutes denial of autonomy and agency over our own lives. Substituted decision making is rampant in the lives of women with psychosocial disabilities. Legislations across the world still use derogatory language such as unsound mind and put us under guardianship, conservatorship etc in direct contradiction to the CRPD.[7] These are done, once again, in 'our best interest', to 'protect ourselves and society from harm'. '*Guardianship, as found worldwide, has not protected anyone, but rather, has been used to remove all resources and powers of a person, ultimately rendering them 'civil dead'. This is as good as 'legal shackling', over and above the physical shackling that persons with psychosocial disabilities are subjected to'.*[8]

The denial of legal capacity also results in a cascading loss of rights and entitlements, including vote and participate in public life; access to justice and seek legal remedy; own and manage property or a bank account; have a family and custody over children; exercise contractual capacity; and, allowing proxy consent, guardianship, and institutionalization.[9][10] Women with psychosocial disabilities do not have the right to bodily autonomy which implies that decision about our own bodies is often taken by families or guardians often at the behest of service providers. Additionally, women with disabilities are more susceptible to gender-based violence, exploitation, and abuse.[11] Within health care settings, women are regularly exposed to violence, abuse, coercive practices[12] such as forced sterilization, forced abortions, forced hysterectomies, forced medications, if they conceive, their children are taken away, forced treatments like electroconvulsive therapy, psychosurgery, cochlear implants etc.[13] These coercive and involuntary practices are further exacerbated in institutions and closed-door settings.

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[5] TCI. (2023). *TCI's written submission to the Committee on the Elimination of Discrimination against Women (CEDAW)*. https://tci-global.org/wp-content/uploads/2023/07/TCI-Global_Submission-for-General-discussion-on-EIRWDMS-CEDAW.pdf

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

[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).

[8] *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).

[9] Legal Capacity Laws, Policies and Practices, and Women with Intellectual and Psychosocial Disabilities. Concept note. (2023). Available at: https://tci-global.org/wp-content/uploads/2023/02/Legal-Capacity-Roundtable_TCI-UN-Women_Concept-Note_Final.pdf

[10] Inclusive Justice: Leaving No One Behind. (2023, February 14). https://www.youtube.com/watch?v=cKIK1Mc8rSg

[11] A/67/227, para. 13 (Report of the Special Rapporteur on violence against women, its causes and consequences: Advancement of women)

[12] E/CN.4/1999/68/Add.4 (Report of the Special Rapporteur on violence against women, its causes and consequences, Radhika Coomaraswamy, in accordance with Commission on Human Rights resolution 1997/44.)

[13] TCI. (2023). *TCI's written submission to the Committee on the Elimination of Discrimination against Women (CEDAW)*. https://tci-global.org/wp-content/uploads/2023/07/TCI-Global_Submission-for-General-discussion-on-EIRWDMS-CEDAW.pdf

An infringement on of women's reproductive rights constitutes violence towards women.[14] This elaboration emphasizes the harsh reality of systemic violence against women with psychosocial disabilities in all spheres. Even in the 21st century, women with psychosocial disabilities are treated as second class citizens, routinely denied legal capacity and subjected to disability-based deprivation of liberty. And these are often perpetrated by those who are entrusted with 'care' perfoming duties- service providers, families, guardians and communities.

Recognizing who are the 'care givers'

This leads us to the pressing question and one which is presented as an incoherent mix in the current discourse around care and support; *who really are the care givers*? There have been simultaneous mentions of paid and unpaid care givers which rings alarm bells for us. We reaffirm that there should be a *clear discussion on who are the caregivers, especially the paid caregivers*. It is not just families or community persons. For women with psychosocial disabilities, mental hospitals, mental health professionals, social service providers are all included in the ambit of caregivers. Families also often work closely in partnership with such service providers, at the cost of the expressed will and preference of persons with psychosocial disabilities. The rationale for this discourse seems to provide safeguards for unpaid care givers. But it does not prohibit the paid care givers from enjoying the benefits[15] (i.e. equal rights as care receivers). There will be a tsunami of care givers (paid), including institutional care providers, co-opting the sentiments and the provisions of this discussion, if allowed into the purview *and* given equal rights as the primary rights holders.

As many persons with psychosocial disabilities will confirm, institutionalization is initiated often by family members and care givers (both men and women). The politics of 'community' and 'family' has been deconstructed in all its power dynamics by feminism. However, the current debate romanticizes 'caregiving' and makes it a one way street without any complications or corruptions. While family empowerment is all important, this is not achieved by brushing away the complex relationships held within families, conflicts therein, and restrictions in access to resources by persons with psychosocial disabilities. The denials of the right to full personhood and right to legal capacity is not discussed in this sphere as it is these larger practices of guardianship, given to care givers, that usurps all human rights of persons with psychosocial disabilities. Further, as is widely known, 'women' within family contexts rarely have the power to have control over resources (e.g. care giver allowances). It is held by the patriarchs in the family.

[14] E/CN.4/2002/83 (Report of the Special Rapporteur on Violence against Women, Its Causes and Consequences, Radhika Coomaraswamy, submitted in accordance with Commission on Human Rights resolution 2001/49)
[15] A/HRC/52/52

Being care givers of our own families and communities, as women with psychosocial disabilities, we do whole heartedly acknowledge that caregiving is a labour-intensive and demanding task and is predominantly undertaken by women. We believe it is crucial that this invisible labour is valued, and efforts should be made to recognize, reduce and redistribute this work.[16] However, we would also bring attention to the fact that is extremely important to critically examine, acknowledge and address the inherent power dynamics and hierarchies embedded within care giver-receiver relationships. Moreover, when service provider (paid care work relevant to persons with psychosocial disabilities) rights are brought in, without any acknowledgement of the harm caused by them, along with will enter all the impunity clauses, 'best interest' and 'least harm' arguments and practices. Considering the decades of violence by public and private service providers, particularly institution-based ones, against persons with psychosocial disabilities, this particular formulation on 'care' is fearful and intimidating.

Economic costs of care

In the current discourse on care and support, the intersection of gender and care work emerges as a focal point mainly in the context of economic cost of care giving. Indeed, as stated above, the invisible labour of women and other caregivers must be given its due recognition. There would be no disagreement on this. But the flip side must be recognized as well: It pitches disability rights versus women's rights and creates an unnecessary polemic at the policy level. We don't have to diminish disability rights in order to uplift women's rights. We don't have to downgrade community life in order to stress the importance of services. TCI confirms that in our experience, societal norms and policy frameworks *fail* to recognize women with psychosocial disabilities as care givers. The current discussion mentions persons with disabilities as being care receivers and care givers. However, the contextual realities and legal barriers paint a much grimmer picture of the situation for women with psychosocial disabilities.

We remain gravely concerned about prospects of monetization of care giving among families and communities and what it means for persons with psychosocial disabilities. What does it do to our identity if our family members or peers or community persons are paid to take 'care' of us? This fosters a deep sense of self-doubt as it reinforces the perception of being a burden or objects to be taken care of in exchange of a compensation. That is not a healthy space to occupy as it is detrimental to one's identity and dignity. When care becomes a commodity, it transforms into an economic transaction, embedding service-provision mentality, hierarchies and dynamics within family and social relationships[17]. This also carries the danger of 'care' becoming punitive, within domestic and community spaces, and as a method to exercise control.

[16] United Nations (UN) Secretary-General High-Level Panel on Women's Economic Empowerment. (n.d.). *RECOGNIZING, REDUCING AND REDISTRIBUTING UNPAID WORK AND CARE*. https://www.unwomen.org/sites/default/files/2023-01/hlp-wee-working-group-paper-driver-3-en.pdf

[17] TCI. (2023). Working Group on Community Inclusion (WG-CI) Strategy Meeting: A Learning Report. Available at: https://tci-global.org/wp-content/uploads/2023/10/WGCI-Startegy-Meeting-Learning-Report.pdf

In a recent meeting of our members from 24 countries, while deliberating over the care agenda, we heard mentions of 'paid to abuse', 'just need care, forever the care receiver' and 'whose voice is actually being heard or who is in power' and 'I am the carer, you talk to me, I decide'. These statements not only reflect the apprehensions, but the lived experiences of the complexities and harmful dynamics set within some social relationships. Monetizing care giving also reinforces gendered division of labour, where you formalize care giving as 'women's work' and maintain the status quo.

It is pertinent to emphasize that women with psychosocial disabilities are not a homogenous group. We also have a diversity of experiences within ourselves. While some of us have been fortunate to experience loving, nurturing relationships, some of us have endured torturous, neglectful and unloving relationships. Despite these diverse experiences, one truth remains universal: care giving, interdependence and mutual support are fundamental human qualities. Commodification of care risks introducing vested interests into intimate social units, such as families and communities, corrupting this human expression, diminishing voice and will of persons with disabilities, and fracturing communities.

'*With respect to the 'care' and 'support' debate, 'Care' was one of the earliest notions to be co-opted by health and social service systems. However, if we sever this concept from these services, and place it back within community and human engagements, we can see the importance of the CRPD guidance on individuality within the context of interconnectedness. In the psychosocial support works that TCI has been engaged in, we see a lot of transactions around 'care giving', typically by family members, especially women who carry a double or triple load of work. Hence, there is talk about 'burden of care'. Here, because care is seen as a 'burden', and persons would like to minimize that burden, persons giving care become custodians and guardians offering control rather than determine the nature and quality of support. But we should not throw out the baby with the bathwater. There must be ways of retrieving care as a useful concept not necessarily linked with services, nor a 'burden', but linked with strengthening communities and families, creating broader group support systems, in the context of providing individualized support to persons with disabilities. We in TCI lean on the side of retaining 'care' as a human quality that cements communities together, but delinking it from services*'.[18]

In conclusion, we present the following recommendations:

1. Prioritize working with an **intersectional lens focusing on gender and disability**. No work on care and support is possible without including the experiences of women with disabilities, particularly women with psychosocial

[18] TCI (2022). TCI positionality on Community Inclusion. TCI Global, Geneva. Available at: https://tci-global.org/wp-content/uploads/2024/07/TCI-Positionality-on-Community-Inclusion-2022.pdf

disabilities. Truly and meaningfully **engage women with psychosocial disabilities** in all the discussions and discourse.

2. Strong focus should be on **complete implementation of the CRPD and UN Guidelines on Deinstitutionalization**. These frameworks provide comprehensive guidance on developing rights-based community support services and support systems that centre principles of equality, non-discrimination, respect for inherent dignity and upholding autonomy including decision making of persons with and without disabilities.
3. Emphasize **support over care** by developing robust support services for persons with disabilities and care givers. Establish strong social protection measures and implement gender parity measures to reduce and redistribute care work.[19]
4. Address **systemic violence and dismantle legal barriers** for women with psychosocial disabilities. Repeal discriminatory legal frameworks, restore full legal capacity, abolish substituted decision-making regimes such as guardianship and eliminate coercive practices within homes, communities and healthcare settings.
5. Establish **clarity on the roles and distinctions between paid and unpaid care givers**. Recognize that caregivers, in the context of women with psychosocial disabilities, encompasses a wide spectrum of actors such as families, neighbours, peers, healthcare providers, institutional staff, social workers etc.
6. **Caregiving is a skill** and requires support and capacity building initiatives. Caregivers usually express uncertainty about how to handle challenging situations, often leading to institutionalization of persons with disabilities. To address this and support them, there should be a focus on building their capacity, providing them resources and necessary knowledge to facilitate rights based and effective support.
7. Exercise **utmost caution in the monetizing of care giving**, especially within families and communities. Introduce other forms of social support provisions for care givers such as peer support, peer respite spaces, subsidies or vouchers to access needed services, support with employment or education of care givers, self-care skills, pension schemes, health benefits etc.
8. **Retrieve care as a useful concept** not necessarily linked with services, nor a 'burden', but linked with strengthening communities and families, creating broader group support systems, in the context of providing individualized support to persons with disabilities.
9. Conduct **awareness and sensitization activities**, challenging the deep-seated stereotypes related to care work as unskilled, or 'women's work'. This can also be one way to reinforce the message around care being a shared responsibility, irrespective of gender, age, social standing etc. Additionally,

[19] CEDAW/C/GC/40

create awareness on upholding the dignity and rights of persons with psychosocial disabilities in all aspects of support provision.

Contact:

Transforming Communities for Inclusion (TCI Global)
secretariat@tci-global.org
www.tci-global.org