



Report on “Re-Imagining Services in the 21st Century to give effect to the right to live independently and be included in the community for persons with disabilities”.

Submission by Transforming Communities for Inclusion (TCI)

Inputs sent to hrc-sr-disability@un.org on **14 October 2022**

Transforming Communities for Inclusion (of persons with psychosocial disabilities) is a global organization of persons with disabilities (OPD). TCI is membership based, focused mainly on the formation and empowerment of OPDs of persons with psychosocial disabilities at the national level. TCI is a post CRPD movement, with a focused vision on the realization of the CRPD for all persons with psychosocial disabilities, specifically Article 19, on living independently and community inclusion.

TCI was an active participant in many of the global initiatives especially those emanating from the different offices of the HRC on general comment, resolutions, guidances, reports, etc. relating to ‘mental health and human rights’. Our members are actively engaging with the CRPD monitoring processes relating to their countries, as well.

TCI is appreciative of the recent efforts, coming in the wake of the adoption of DI guidelines, of the OHCHR to develop reports on community support services and systems.

General framing for the report:

As a member of the GCDI (Global Coalition on De-Institutionalization), TCI contributed to the efforts of the CRPD Committee to the Guidelines on De-institutionalization, including during emergencies¹. This is the most recent elaboration by the CRPD Committee on Article 19 and living independently, among various other relevant articles, drawing from General Comment 5 and expanding on the substantive interpretation of this article. We recommend drawing from the DI guidelines in the proposed report, as the guidelines details several practical steps to full inclusion in the community. Importantly, the guidelines on DI also provides guidance on the approach of seeing persons with psychosocial disabilities as a historically oppressed and persecuted group, who must receive recognition as such, along with reparations and redress by states parties and its actors. Any study on “community inclusion”, we propose, should build on this guidance, with persons leaving institutions and settling in communities, receiving validation as victims of historical oppressions and reparation for violence done to them. The report could also draw from a cluster of reports by leaving Special Rapporteurs (Disabilities, Health) on supports, deprivation of liberty, highest

¹ <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd273-guidelines-deinstitutionalization-including>

achievable standards of health and wellbeing, etc.

In another recent effort, TCI contributed to the consultative process on the “Mental health, human rights and legislation” draft guidance, published jointly by the WHO and the OHCHR. This guidance, if adopted, will maintain the *status quo* on the culture of institutionalization and the biomedical dominance of psychiatry; It will not address the systemic fault lines in policy making (incapacity laws, forced treatment / coercion, guardianship) that has, over decades, denied autonomy, identity and personhood to persons with psychosocial disabilities. This initiative within the OHCHR runs counter to various other initiatives to harmonize policies and practices with the CRPD. We have strongly advocated the withdrawal of this guidance.

Our submission is drawn largely from our experiences in the Asia Pacific region and experiences of providing some of the largest community support services in the global south for a decade or more. Our learning is that the path to community inclusion must cover the following actions, supported by governments:

- a. Providing persons with psychosocial and multiple disabilities access to *mainstream services* (e.g. health care, education, skill development, housing, food and nutrition, etc.)
- b. Providing persons with psychosocial (and other) disabilities with *Community support services* (pension schemes, disability card, social protection schemes, personal assistance, domiciliary card, formal psychosocial support services, etc.)

Further, not only some services must be reimagined, some other services must be erased. The report must include the following actions by governments of **removing certain legal and allied “services”** associated with the mental health and disability based carceral systems worldwide by

- c. Enabling de-institutionalization and prevention of institutionalization by dismantling the legal, physical, human resources and financial infrastructure upholding the culture of institutions.
- d. Removing the legal, social, attitudinal barriers that prevent persons with psychosocial disabilities from living uninterrupted lives in the community (repeal of legal incapacity provisions, mental health legislations, prohibiting the “bundling” of social economic services with medical compliance, gatekeeping on decision making and various associated surveillance and control provisions found in a variety of laws and practices for implementing disability-based detention.)

Provision of comprehensive services in tandem with removal of services that create barriers, will enable communities to own and build on their immediate household and community support systems, transforming communities towards inclusion. There is the view that accelerating community support services will make institutions go away. However, as long as legal barriers are provided as a solution and a “service”, exclusion will persist, and lives in the communities will always run the risk of having their lives interrupted and fragmented, exposing them to the risks and violations of inhuman, degrading, torturous treatments.

While ‘individualized support’ (e.g. personal assistance) for persons with disabilities is illustrative of one kind of community service action, it may become restricted to high income countries that can afford this service. Secondly, it may not be acceptable to communities which are not individualistic and to impose culturally inappropriate solutions has not worked in other development contexts. In TCI’s experience in the global south, particularly Asia Pacific and African regions, there is a positive experience of a support that is relational and communal, tied to social networks and is coming from experiencing and resourcing the ‘collective’ experience of trust, affection and belonging (neighbours, extended families, nearby support persons such as friends or acquaintances etc.) During the COVID pandemic, several persons who were home bound under the lock downs, had a revival and intensification of their psychosocial disability experiences, because they could not access their support systems (peer group, friends, support group, etc.).

We also heard various testimonies that during emergency situations (such as earthquakes or floods), many services fail, however, it is the community actors and networks facing common dangers, that come together to rescue, provide safety, address basic needs and reconstruct. While there could be a view that these ways of 'being' are 'cultural', 'peculiar to some countries or regions' or 'too abstract', however, the search for the experience of 'community' built on a common interconnectedness and belonging is universal and is also central to the CRPD. Some concepts of the CRPD such as 'evolving capacity', 'living independently *and* being included', 'reasonable accommodation', 'support in decision making', etc. cannot be fulfilled without this communal notion implied within the ambit of individualized support.

TCI differentiates 'Community support services' from 'Community support systems'. *Community support systems*, depending on the local contexts, may include a neighbourhood support system, simple befriending actions, altruistic actions, foster support, neighbourhood supports for homeless persons with psychosocial disabilities, group support, peer to peer support, support for exercising legal capacity, contributing to peaceful communities, support to negotiate family, conflict reduction in the household and community, reducing gender violence, enabling community negotiation processes to prevent institutionalization (using community justice systems), promoting 'bystander ethics' in neighbourhoods, access to play, sport and recreation groups, etc. 'Crisis support' often evokes many of these elements of supportive human exchanges. This has been referred to as a '*circle of care*' in some of the programs TCI has been associated with. To establish some SDG goals such as gender equality, reduced inequalities, sustainable cities, institutions that promote peace and justice, etc. are closely tied to community development, involving human value based exchanges going beyond services.

Good practice examples, with training, evaluation and monitoring systems exist, as illustrative, from the global north and the global south. Independent peer networks in USA and elsewhere is one such, developing independent peer support systems worldwide. Bapu Trust from India is another example from the global south, which is committed to a 'zero coercion' approach to inclusion of persons with psychosocial disabilities. Examples of peer, group, arts based, trauma informed, befriending, 'just being', crisis support etc. demonstrate such relational support systems.

While the forthcoming report may indeed reasonably contain its scope to community support services, however, it must address the impact of those services in terms of whether they promote and enable caring community support systems, or not. Collapsing community support systems within the scope of community support services will diminish the potential for inclusion within families, neighbourhoods and communities.

For example, "zero hunger" is still a pipe dream for many households in low-income communities in our regions. Having to scramble for food pushes the survival button and makes persons fend for themselves. This may seem like an individual choice, to ensure one's own access to food at the cost of others'. However, if there was ample food available in the household, there may be more inclusive and embracing conversations there about what people in the household like to eat, sharing of food, etc. adding positivity and cohesiveness to the household and reducing conflict. So while provision of food is the service, the impact it has on households, and their communal behaviours, is the indicator, whether the service led to inclusive sentiments and practices. So also, with housing, social protection, etc.

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. So there is talk about “burden of care”. Here, because care is seen as a “burden”, and persons would like to minimize that burden, willy nilly, persons giving care become custodians and guardians offering control rather than 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, in the context of providing individualized support to persons with disabilities. We in TCI lean on the side of retaining “care” but delinking it from services.

Some specific feedback

Policy level principles: Article 19 has been included as part of new emerging policies, however this is countered equally by the number of new mental health laws coming up in the regions. Further, no specific budget is attached to creating the legal or policy environment for implementation of these policies. Even though the WHO withdrew their old resources on mental health law, countries continue to produce mental health legislations and alongwith, institutions. In Kenya for example, after a recent amendment of older mental health laws, the Kenyan government has been constructing mental asylum of “international standards”. Commonwealth nations in the regions, countries with new mental health laws have a growing number of mental asylums, with governments not mobilizing funding for community support services. While mental asylums are largely considered as “hospitals” they are not brought into regulatory frameworks of health systems in general and tend to remain in a regulatory silo, thereby not being regulated within bio medical monitoring frameworks. The populations living inside these institutions are not considered as “persons” and therefore are disqualified from any further service or recognition as citizens of the countries. These blind spots (where institutions are not visible in monitoring and populations living there are not visible in recordkeeping) must be addressed. **The report could consider how to reclaim the personhood of institutionalized persons, in the process of their de-institutionalization, so that they can have a foothold in the arena of services.** The report could emphasize moving mental health services into social care (through providing specific psychosocial services such as counselling, arts based supports, trauma informed support, group support, support for victims of domestic violence and crisis support) and delinking this pathway from referral to rehabilitation centers, half way homes and mental institutions are important service delivery reforms of the future.

AAC Communication: Widely in the disability sector, in our experience, **we have not found any discussions, initiatives or programs about supporting persons with psychosocial disabilities (including autistic, neurodiverse persons and persons with intersectional identities) with alternative augmentative communication.**

There is usually no time window between the perception of an ‘episode’ or a ‘crisis’ by service providers and the ‘SOS’ / ‘emergency’ treatment started, frequently without giving any choice to the person with the disability. Biomedical dominance is one part of the reason, where institutionalization and forced medications are started too quickly without allowing time for community conflict to deescalate or personal insight to set in. Since coercive treatments are prioritized over human rights in the mental health care system, ‘free and informed consent’ defined in a restricted way, with the allowance of third-party decision making, serves as a barrier to the realization of autonomy and legal capacity. Coercive “services” and cadres working in this sector, must be dismantled. There is no culture of communication within these practices.

Another reason is the lack of recognition in government policies and programs, of even the need

for AAC in the context of this constituency. Even with international aid, no investments have been made on developing, piloting new or documenting existing diverse range of alternative, augmentative forms of communication that are useful and supportive for our constituency. Easy Read materials are not considered as relevant for our constituency. References to “nonverbal” communication is not very clear (For example, does it mean sign language?). This must be clarified in the report. Several OPDs in the global south have been using, for over 2 decades, integrated Arts Based support measures to communicate with persons who are not in a position to communicate using language. Providing the necessary time to lapse, even if in the safety of silence, for a person to communicate safely is of prime importance as a form of support. Quiet spaces, ‘being with’ rather than ‘doing to’, ensuring that communications are supportive and not critical, are important elements of safe communications.

Business and human rights approaches: What is called the ‘third sector economy’ (ie. Establishments to serve social sectors not covered by ‘public sector’, government or profit making establishments) are typically the ‘not for profit’ sector. This sector draws huge capital especially in middle income countries and the global south. In a move towards self-reliance as well as diminishing the human rights violations, there is emphasis by governments on making the rights real and also vision and strategy for ‘sustainability’, including financing sustainability. The third sector contributes a lot to this vision and strategy, drawing also from international aid money. The third sector has its own value base, value transfers and transactions, not all of them monetized to the last detail. There is regulation of the third sector and its capital in many countries in the global south, often, maybe too much. The third sector, further, buffers the spin offs of the business sector, for example, by poverty reduction actions, addressing hunger, violence, etc. Increasingly the financing mechanisms of the not-for-profit sector stands in for civic engagement and development, where for profit entities have not entered. In several countries the CSR (corporate social responsibility) policies and initiatives have already brought about shift in capital more in the direction of not-for-profits, and associated regulatory changes are more entrepreneurial, within the scope of non-profits. While there are “shareholders” in the equity and neo liberal markets, in the social sector driven by nonprofits, there are “stakeholders”. There is the attempt in some countries (e.g. India) to bring in a “Social stock market” for social organizations to build their capital based on values and community engagement. There will always be need for philanthropy, not every community engagement is a service and not all services can be purchased. To make all community actions monetized will take away from the spirit of our common spirit of human support and connection. Human rights and business can sometimes lead to contradictory outcomes (for example, private mental hospitals- the profit motive working in tandem with a mental health law allows for profiteering, while human rights are seriously violated).

On incentivizing innovation: An additional concern to be added here, is, “How do you incentivize providers using traditionally given oppressive models to leave or to divert from the market they were traditionally serving?” There is a big need to incentivize persons / employees / trade unions working inside mental hospital and other institutional facilities (as defined by the DI Guidelines, to divert this huge labour force into other areas of occupation. Such diversion and incentivization should include training and capacity building so that they are cleansed of their institutional filter and start to learn new professional skills, behaviours and attitudes. It is important to work with the International Labour Organization (ILO) among other international agencies, studying the potential of the labour force needing to be diverted, opportunities that can be created and a kind of road map for country governments to consider.

It is important to visualize the kind of workers needed at the grassroots, supervisory and programs management level, to dilute the 'expert driven' way of providing services. In programs that TCI has been associated with in India, Thailand, Nepal, for example, programs are led by persons with disabilities. Such initiatives must be recognized by governments, and supported. For building inclusion in the community, persons with lived experiences of disabilities are a great resource, however, they frequently do not have opportunity.

Minimum wage laws and career growth for cadres: Role of community based workers as 'all purpose' or as single purpose ('mental health champion') has to be reviewed and redefined. Government / NGO grassroots cadres working in the grassroots are underpaid, contractual, and often loaded with myriad commitments to fulfil all development agendas in the communities. In government run 'community mental health', the opposite happens- workers are taught to 'identify mental disorders' and escalate the referral to psychiatrists for drug prescriptions or institutions. Differentiation and specialization in the cadres is necessary for them to be able to contribute in an effective manner, developing leadership and innovation at the community level and enjoying their achievements in witnessing change (in the individual as well as in the family and community). In TCI's work on providing "inclusion services" (covering a wide range of mainstream, community-based services as well as support systems)- field cadres have well defined diversified roles- 'family support' role, 'community mobilizer' role, 'role for providing support through self care and individual support', 'referral and networking' role, etc. to name a few. Senior management spends time developing grassroots roles and recruitment, creating a career path, capacity building for growth and leadership creation are very important organizational activities. Some team members may adopt multiple roles in their job description. However, in this diversification, the multiple pieces needed for full inclusion to happen, are addressed.

Lessons learnt to build momentum on Article 19: Inclusion is a vision that appeals to all stakeholders. TCI chose to name itself as 'transforming communities for inclusion' at the local, regional as well as global levels, rather than an organization of 'users and survivors of psychiatry'. A substantial amount of time and effort in TCI goes in engaging our stakeholders (INGOs, donor agencies, UN agencies, service providers, etc.). The momentum was accelerated by TCI and our members' efforts to influence the cross disability movement to think and practice Inclusion. Slowly the entry point shifted from "mental health" to "inclusion", a lot of it propelled by TCI advocacy- This is named as the "entry point issue". We were hugely supported in this by the International Disability Alliance, who, through their flagship program BRIDGE brought palpable values and a community of practice around Inclusion. The shift in power, giving voices back to persons with disabilities, the insistence by OPDs on the practice of full and effective participation, emphasized by the IDA and their partners in their work, their partnership over UN processes and initiatives, brings a new kind of emerging relationships at the global level on the critical and central role played by OPDs in defining the discourse on Inclusion.

Thank you.