TCI positionality on Community Inclusion

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A note of thanks

We thank the multiple meetings, experiences and discussions with our founding members, senior leaders, peers, donors and allies over the years. These discussions and discourses led to the development of this paper and contributed to the clarity on the concept of community inclusion and what it means for us, as persons with psychosocial disabilities. A special mention to our donors; Wellspring Philanthropic Fund, Open Society Foundation and International Disability Alliance for their constant encouragement and unwavering support. We also acknowledge and honour our oldest founding member, Bapu Trust for Research on Mind & Discourse for providing us with high quality experiences of inclusion works in India. The idea of inclusion originated from the grassroots works of the Bapu Trust strengthening our understanding of inclusion of always keeping the person at the centre of it all. We express our heartfelt gratitude.
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1. About TCI

Transforming Communities for Inclusion (of persons with psychosocial disabilities) is a global organization of persons with disabilities (OPD)\(^1\). 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.

In 2018, the Bali plenary\(^2\) was held with participation of 21 countries and over 75 participants and led to the adoption of the Bali Declaration\(^3\). It became a landmark event and a rallying point of TCI and continues to influence the global discourse on the inclusion of persons with psychosocial disabilities. The primary focus of the plenary, among other issues, was to reframe our advocacy from ‘mental health’ to ‘inclusion’ and by shifting the ‘entry point’ to the development sector, inclusive of but not restricted to healthcare sector.

2. Background

We, as a movement of persons with psychosocial disabilities, ‘mad’ persons, persons of ‘unsound mind’, persons with atypical / neurodiverse identities, persons with intersectional disability identities are left behind most frequently in community development initiatives, as are other underrepresented groups of persons with disabilities. Our choices of identities, reflecting a diversity of development needs, comes with request to a variety of stakeholders, including mental health service providers, to consider programming for an outcome of our inclusion in various community-based plans, policies, laws, budgets at global, regional, national and grassroots levels. Recurring occasions to continue to make this request for our inclusion to a variety of stakeholders, is given to us by the Convention on the Rights of persons with disabilities (CRPD)\(^4\), particularly the heart of the Convention, Article 19 on the Right to live independently and be included in the community. While the General Comment 1 (on Article 12: Equal recognition before the law)\(^5\) and General Comment 5 (on living independently and being included in the community)\(^6\) set the foundation for Article 19, the recently adopted UN guidelines on deinstitutionalization, including during emergencies\(^7\), for the first time, in the history of Conventions and the human rights traditions, provided practical guidance on the right to live in the community and be included as a full human right. TCI was honoured to be a part of the Global Coalition on De-Institutionalization\(^8\), comprising of a group of organizations who supported the Committee on the CRPD, in drafting the guidelines.

Some national governments have adopted Article 19 into their disability legislation, but have not implemented those provisions. Some governments have included in their mental health law, the legal

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\(^1\) [https://tci-global.org](https://tci-global.org)
\(^2\) [https://www.tci-global.org/bali-plenary-report/](https://www.tci-global.org/bali-plenary-report/)
\(^3\) [https://www.tci-global.org/bali-declaration/](https://www.tci-global.org/bali-declaration/)
\(^8\) [https://gc-di.org](https://gc-di.org)
improbability of it notwithstanding: Having the right to live freely in the community as a provision in a deprivation of liberty law, that has coercion and custody at its core, is a legal curiosity. Investors, donors, bilateral agencies, international co-operation agreements, etc. have not invested on the right to live independently and be included in the community, as an independent strategy. While there are now international legal and guidance documents mandating, elaborating and expanding on the full potential of this human right to Inclusion of all persons with disabilities, INGOs, technical support agencies, policy makers and bureaucrats, law makers and the diversity of service providers take a charitable or welfarist approach to service provision. The number of ‘sheltered’ workshops, expert driven mental health services, other ‘special’ settings, ‘special’ wards or institutions for persons with disabilities has not come down in the last 15 years. Indeed, worldwide, with the rising number of new or amended mental health laws the number of forced admissions has risen phenomenally. The Corona pandemic evidenced more, not less, institutionalization for a wide range of persons with disabilities.

The phrases, ‘zero coercion’, ‘transforming mental health’, ‘transforming communities’, etc. are heard in many global policy circles today. Often, our vision and ideas of community inclusion either gets co-opted by various stakeholders or gets construed by narrow definitions boxing us into the confines of availability of health services only. Mental institutions are found in the list of ‘services’ offered, especially against the growing tide of new or amended mental health laws. TCI, as a global OPD, the largest representative voice of persons with psychosocial disabilities and varying identities thereof, with a membership spread across Asia Pacific, Africa, Latin America, UK and Canada, lays down our positionality on community inclusion through this paper.

3. What do we mean by a community?

In the CRPD, Article 19 makes a direct reference to ‘Community’ 7 times. Indirectly, the presence of community is felt in every article, including in the description of disability as the experience of impairment in interaction with social, legal and attitudinal barriers, notions of discrimination, reasonable accommodation, evolving capacity, etc. The CRPD brings together, in interesting ways, the idea of individual human rights in the context of social living and interdependence; Or, as General comment 5 elaborates, ‘exercising freedom of choice and control over decisions affecting one’s life with the maximum level of self-determination and interdependence within society’. General comment 5 further recalls this recognition of the social aspects of independence from the Universal Declaration of Human Rights, including ‘the interdependence of an individual’s personal development and the social aspect of being a part of the community’. While the human rights paradigm puts the person with the disability at the very centre, several articles mandate the full engagement of the social, relational aspects of community life. This is not specific to persons with disabilities, but to persons per se.

The meaning and description of ‘community’ changes across different geographies, populations and contexts. The CRPD recognizes that the values of interconnectedness and belonging are universal and common globally. There have been very few attempts to describe or define a community from a national policy point of view. In our years of experience with our founding members, who are all grassroot organizations of persons with psychosocial disabilities, we have tried to emulate an elaboration of what we mean by ‘Community’ and attempted to provide a vision for how an ‘inclusive community’ would

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look. As elaborated in TCI’s submission to the CRPD Monitoring Committee, Day of General Discussion, Article 19\textsuperscript{10}, as a way of framing: ‘Community is proposed to stand for the availability of ‘social capital’ and ‘local actor networks, a collection of individuals, groups, families, neighbourhoods in local environments who come together, sometimes to reach a reasoned out functional objective together, or sometimes to connect on human basis for sharing and caring for each other without any necessary preconditions or proposed outcomes. Such networks bind families, individuals, cattle, plant life, other life forms, inanimate objects, land, water, food, and other actions and artefacts of human social living into an organic whole, embodying a vision for a sustainable world (contained within extant Development frameworks such as the SDGs). We need to recognize the importance of transforming communities so that they become emotionally sustainable, to facilitate the inclusion of everybody, and for the preservation of a peaceful and caring planet.’ TCI conveys here, that the ecology of communities is biodiverse and neurodiverse and that, a ‘community’ is more than a set of services or service providers. Any intervention, service, policy or law should contribute to the sustainability of this organic ecology.

These ideas were drawn from a variety of theoretical debates and resources, including the Actor Network Theory; the concept of ‘social capital’ being increasingly used in health care and the development sector; the Capability Approach used in social theory and development economics; the idea of justice linked to autonomy and choice rather than institutions; the concept of cultural competency; and so on.

The ‘actors’ and ‘networks’ aspect were argued forcefully by Bruno Latour, who clarified that all objects, phenomena and processes are at the same natural, social and discursive\textsuperscript{11}. The relational, social aspects of participation, trust, networks and co-operation is debated within writers engaging the concept of ‘social capital’, especially in the field of health\textsuperscript{12} and mental health\textsuperscript{13}.

McKenzie, Whitley and Weich\textsuperscript{14} write that ‘[S]ocial capital may yet prove to be an important mediating factor between a community, the collective attributes of its members and individual health’. As they explain, social capital is an ecological concept and describes the property of groups rather than of individuals. Bringing in the relational aspect in Capability Approach, absence of impediments to be able to utilize opportunity is central to the enjoyment of freedoms\textsuperscript{15}, and the Capability Approach is not inconsistent with the pursuit of wellbeing and happiness.

\textsuperscript{10} TCI. (2015). \textit{Submission to the UNCRPD Monitoring Committee, Day of General Discussion, Article 19.}


Connecting the dots across a number of theoretical resources, TCI evolved a rich picture of an inclusive community. The framing was supported by the grassroots experiences of our members, implementing inclusion programs in different locations in Asia. Like clear water flowing above the debris and stones in a stream, community life is a buzz of free flowing events, processes, actions and actors, determining the course of a community transcending different types of service providers and civic administrators.

4. **What do we mean by inclusion?**

It is an adage that ‘Inclusion’ is important to all persons with disabilities, and indeed, for any person located anywhere in the world. As a way of life, inclusion is what everybody wants, whether having a disability or not: belonging, family, community, support, friendships, etc. Services are a part of this spectrum of needs: housing, financial inclusion, employment, adequate standard of life, leisure activities, political participation, sport, etc. It is no different for persons with psychosocial disabilities. Indeed, when all the social, economic, civil, political and cultural human rights are realized through effective states policies and a wide spectrum of good quality social and economic services, a network of support services are enabled and person has access to resources. There are neglectful aspects of community life such as inequality, violence, withdrawal of food and fluids, casting out, denying available resources, etc. These kinds of discriminatory community processes need to be addressed too, and typically, they are not covered by services. When different forms of normative, attitudinal and resource related discriminations are removed, and persons with disabilities enjoy the same social status on equal basis with others, the outcome of inclusion is obtained. Therefore, inclusion is not only a philosophy or a value; it is not only a spectrum of legal, economic, social, policy and programmatic services; It is also a set of processes and practices of the social groups necessary for disability inclusive community living. Inclusion describes a human ecosystem, where no one is left behind.

5. **What do we mean by community inclusion?**

In the context of persons with disabilities, community Inclusion has been considered a value, or a kind of ideal to work towards, and not a capacity building or a practical matter to be built into programs, policies and community development designs. We have been told that community inclusion is a vague, abstract construct. In recent times, every development practitioner believes that they are ‘inclusive’, however, we have fewer conceptual or practice resources or even shared anecdotal experiences that they are ‘doing inclusion’. Despite evidence to the contrary, mental health professionals believe that medical treatment and institutionalization can cure a person and mainstream them. Providing a service is misconstrued to be an inclusion action and it is only partially so. Addressing legal barriers is not considered within the ambit of inclusion, thought it should be.

The CRPD breathed life into a new human right: the Right to Live Independently and be Included in the community. All persons with disabilities will live in the community and be included to live independently and to participate on an equal basis with others. Article 19 invites an inclusive world for everybody, not just persons with disabilities. Article 19 of the CRPD, read along with other articles, mandates:

- That Persons with disabilities have the right to choose their place of residence, and who they want to live with;
- That some places where they are most often found (e.g. shelter homes, rehab centres, half way homes, mental institutions, etc.) are not ‘places of residence’;
- That, all services be close to their place of residence;
- That, they have access to all mainstream or general services on equal basis with others; as well as all disability specific services as per the diversity of needs faced by persons with disabilities.

Further elaboration on Article 19 is provided in General Comment 5, which begins with the statement that, ‘Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation’. Building on the need for very practical guidance on De-institutionalization, the recent UN ‘Guideline on Institutionalization, including during emergencies’ guides that, for realizing the right to Article 19, persons with disabilities have:

- Enabling legal, policy environments, devoid of barriers to full participation in society and community (e.g. repeal of mental health legislations and dismantling different types of institutions, aggregated living arrangements etc.).
- Access to community support services.
- Access to all mainstream services.
- Access to community support systems.

6. Fundamentals for ensuring community inclusion

In TCI’s decade of experiences in Asia Pacific of providing technical support to one of the largest community inclusion and psychosocial support services in the Global South, we have learnt that the path to community inclusion must cover the following actions, supported by governments:

1. Providing persons with psychosocial and multiple disabilities access to mainstream services (e.g. health care, education, skill development, housing, food and nutrition, etc.)

2. Providing persons with psychosocial (and other) disabilities with Community support services (pension schemes, disability card, social protection schemes, personal assistance, domiciliary, national or election cards, etc.).

3. Community inclusion calls for not just transforming some services but erasure of some legal and allied services associated with mental health and disability-based institutionalization systems worldwide.

4. Enabling de-institutionalization and prevention of institutionalization by

dismantling the legal, physical, human resources and financial infrastructure
upholding the culture of institutions.

5. 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.)

6. Allowing communities, as defined above, to perform some of the support and care functions, as is found in human habitats more naturally, and trusting the processes of community exchanges, trust and negotiations as vital to the psychosocial sustainability of human society and habitats, without interruption by services that create barriers (e.g. mental health law).

7. Governments have a role to play in the removal of barriers, removing or redirecting existing discriminatory services and practices and in not creating barriers to continued community life.

7. Dilemmas and assumptions

We elaborate on some dilemmas and assumptions that the stakeholders holding and nurturing the community development arenas worldwide, have to consider and resolve, so that, normatively and in a practical way, no one is left behind.

7.1 Entry point issue

The first dilemma is the ‘entry point’ issue.

Assumption of service providers- A person diagnosed with a mental, intellectual, chronic health, multiple, autistic, sensory or other disabilities, including those with non-conforming, neurodiverse and intersectional identities, should first get their mental health conditions addressed, before we start on other recovery orientated, social, development linked solutions. Redressing human rights issues within the care system or within the person’s lives is not considered within the ambit of ‘solutions’. People who are pushed into this mental health entry point then become characterised as ‘severe’, often times backed by reductionistic medical assessments, and are denied opportunity to exercise their freedoms, to take risk, learn from and build on their autonomy and capacity to contribute to society. They live in ‘protected’ zones, often times, they get institutionalized.
In our advocacy, we use the ‘3 door analogy’ as a paradigm shifting, CRPD compliant, SDGs fulfilling strategy. The smallest door is the mental / health / care service door, the slightly larger door is the development door and the largest one is the human rights door. Persons with disabilities who enter through the smallest door remain shut in, sometimes literally, inside institutions.

Those who have access to entry through the other doors have a wide range of opportunities to choose their own life path, make choices, decisions and create experiences to learn from. In the grassroots experiences of TCI, no one ‘deserves’ just the mental health door. Everyone, without exception, needs access to Development and Human rights solutions. A few among those may require psychosocial support of their choice. Usually, in our experience, a person who enters through the mental health door, can be shut out of the other doors, or there could be a ‘bundling’ of services with treatment compliance. Taking medicines, reporting to the nearest service, surveillance, compliance with community treatment orders, etc. are leveraged for work, social protection, housing, etc. For the last decade, TCI, along with its members have been working on efforts to influence the stakeholders and policy influencers to think and practice Inclusion. Slowly, the entry point is shifting from ‘mental health’ to ‘inclusion’, a lot of it propelled by relentless advocacy by TCI, our members and leaders. This is named as the ‘entry point issue’.

7.2 Compartementalization of services and sustaining ethically problematic services

Another assumption relates to the compartmentalization of services, fulfilment of one’s role as the ‘service provider’ and keeping to those boundaries, as prescribed by the organizational and program delivery protocols, within health care and development practice. This in turn is driven by curricula and trainings that have not particularly considered the diversity of disability experiences or disability sensitivity, leave alone the vision that no one is left behind.

To give an example, Community Based Rehabilitation (CBR) programs very rarely address the needs of persons with psychosocial disabilities, or address them from a very medical perspective (by making a referral to a mental health facility or psychiatrist.) Mental health services are offered in a silo, with a narrow definition of ‘treatment’, often by using force and compulsion. In many parts of the world, persons with psychosocial disabilities, by the power of law, are denied the right to refuse treatment, which, from a medical ethics point of view, is a non-derogable human right: In health care ethics, a person cannot be denied the right to refuse treatment. By now, with a worldwide uproar about the mental health systems and the human rights violations thereof, including a stream of documents from

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the United Nations\textsuperscript{17,18,19,20}, the limitation of this assumption must be evident. However, policy questions set by international bodies such as the WHO still focus on ‘tertiary care’ [sic] services, counting number of beds, number of psychiatrists, ‘intensive psychiatric care units’[sic] etc. without considering the social, structural causes of psychosocial distress, disturbance and disability. A mental health service can indeed result in exclusion, segregation and seclusion. There are some conventional, but powerful, stereotypes about us, resulting in blind spots in development practice. For example, a widely cited example is about people with disabilities abandoned in cages in Indonesia, during the tsunami in Palu\textsuperscript{21}. Community members climbed to higher ground and responders did not count people in institutions as needing a disaster response.

Having matrices of Service element 1, Service element 2, S3, S4, etc. or combinations thereof, may address the need for an essential social, economic or health care service, but may not have the result of inclusion of the person with the disability in their community, and may not result in independent living. The process flows of these programs, their designs, etc. are not harmonized with the CRPD. They are not geared up for the Inclusion of persons with disabilities, especially those who are most under represented among them. It is important to go back to the drawing boards and test them against inclusion as a legal, policy and programmatic outcome. If legal systems create barriers, and interrupt lives in the community, multiplying community services will not help in realizing the human right to live independently and be included in the community. Legal barriers have to be addressed for people with disabilities to be able to access services.

7.3 Community support systems and community support services

TCI differentiates ‘Community support services’ from ‘Community support systems’. Community support services are as described above, including health care, education, work and employment, sports, leisure, grooming, nutrition, etc. etc.

\textsuperscript{17} A/HRC/44/48
\textsuperscript{18} A/HRC/35/21
\textsuperscript{19} A/HRC/40/54
\textsuperscript{20} A/HRC/43/49
Community support systems, depending on the local contexts, may include a wide spectrum of humane exchanges and processes: Neighbourhood support systems, 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, contributions 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. In fact, while the community support actions can be codified, and counted within a support program, maximum innovations and micro actions happen in this domain. Worldwide, there are such examples of people coming together relationally, functionally and practically to support persons with disabilities, including persons with psychosocial disabilities. While within the medical model, ‘crisis intervention’, involving the law and order machinery is spoken about, ‘crisis support’, in the peer support movement often evokes many of these elements of non-judgmental and attentive and human exchanges, allowing for time to build community support. This has been referred to as a ‘circle of care’\(^{22}\) in some of the programs TCI has been associated with. (Figure 2)

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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 support and 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. 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. Hence, it becomes imperative to always check and be mindful if community support services are promoting and enabling 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.

7.4 Care

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.
7.5 Legal barriers

It is a truism that mental health law is about deprivation of liberty, and therefore, will contravene Article 19, of the right to live in the community. If a person is deprived of their liberty, their right to live in the community is thereby denied. Contradictorily, Article 19 has been included as part of new emerging mental health laws in some countries (e.g. India). Be that as it may, no specific budget is attached to creating the legal or policy environment for implementation of the provision to live in the community, as nearly all the spending is on the ‘deprivation of liberty’ part. Even though the WHO withdrew their old resources on mental health law, countries continue to produce mental health legislations and along with, institutions. 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. 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. It needs immediate consideration 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 and support systems. Governments could remove psychosocial care from health, and place it within social care (through providing specific psychosocial services such as peer support and self-help groups, arts based supports, trauma informed support, group support, support for victims of domestic violence, supporting adolescents bereft of parents and crisis support). This care should also be delinked from referral to rehabilitation centers, half way homes and mental institutions.

In conclusion, TCI has elaborated on a view of ‘community’ which is neurodiverse and biodiverse, and are best visualized as ecosystems. The SDGs provide us with some goals, including Gender Equality, Reduced inequalities, Sustainable Cities and Communities, which require an ecosystems view which is not inconsistent with the CRPD framework. To develop self-reliant communities, capacity building various members and stakeholders on community inclusion is vital. There are dozens of good practice examples, how community supports are enabled and maintained, whether in the global north or the south context. TCI has recently this year, established a ‘Working Group on Community Inclusion’ to further develop the pedagogy and practice of Article 19.