

Working Group on Community Inclusion (WG-CI) Strategy Meeting

A Learning Report



July, 2023
Kathmandu, Nepal

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**Community Inclusion Strategy Meeting
July 21-22,2023
Kathmandu, Nepal**

Documentation and reflections from the meeting

Does ensuring access and availability of services ensure inclusion?

WG-CI members reflected on *if availability of support services or social protection only defines or leads to inclusion*. A perspective in recent global policy documents on community inclusion purports that if all assistive devices, interpretation services, employment, housing, social protection and personal assistance is provided, then inclusion will happen. However, it is still a prevalent notion of the Global North. While social protection and community support services are crucial and must be made available to all persons with psychosocial disabilities, the larger debate remains, what are the additional elements that that will lead to inclusion. There needs to be an emphasis on community support systems by actively engaging communities and families, stronger community networks, strengthening peer support networks and informal support systems. Social capital is an important part of community support system. In many instances, social protection benefits (for example pensions, disability benefits) hardly reach person with psychosocial disability due to family's own perception of legal incapacity of the individual. Having a range of services is needed and must happen and government should take that cost. However, costs and services are not enough to ensure inclusion.

For inclusion to be realized, community factors need to be at work and a wide range of possibilities, within communities should be explored. CRPD Article 8 on awareness raising should be mobilized in profusion, with the message of community inclusion, to effect social and behavioural changes. Such efforts must be demonstrable and studied as a part of transformative change. Interventions and microactions, with the support of community members and stakeholders to ensure inclusion are needed, for example, when witnessing rights violations. Family members and those in the person's 'circle of care' must be mobilized in order to bring an existing support system closer to the person. Such interventions could include reconciliation, conflict reduction and negotiation methods at the household and neighbourhood level. Connecting persons with psychosocial disabilities to supportive peers, friends and those trusted people in their networks, with whom they may have lost contact, is useful. Engagement with local service providers and other stakeholders for transforming services towards inclusion of persons with psychosocial disabilities is an important step to deepen community engagement on the subject of inclusion. Funding a separate stream on community strategies for inclusion is necessary for strengthening communities around the thematic of 'inclusion' of persons with disabilities. Communities can be engaged as a watchdog and a safeguarding mechanism to check whether services, benefits and pensions

are going to the individuals in need; and take local action as a responsible community member, when rights violations happen.



Do the rights of care givers are equivalent to care receivers?

There was a discussion on the Care Agenda¹ being ushered in high level political spaces where support is being treated as care. This proposed policy narrative emphasizes monetizing care giving; brings gender equity and justice issues to the forefront as a majority of care givers are women; and seeks to equate the rights of care givers with the rights of care receivers. Indeed the invisible labour of women and other care givers 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 (with assumptions such as, 'family members must be given the money to perform a role like a service provider, otherwise, they will violate human rights'). This dilutes the natural trust that may exist within families, communities and divides interests.

Members from the Global South deliberated that communities and social networks care for each other as it is a human quality to care but monetizing this care giving will create vested

¹ <https://tci-global.org/wp-content/uploads/2023/06/Final-Support-versus-care-TCI-response-to-A-HRC-52-52.pdf>

interests within social units such as family, subdue some marginal voices and lead to break up of communities.

Another, more frontal thread of discussion is to reflect upon who are the care givers. It is not just families. Mental hospital, mental health professionals, social service providers are all included in the ambit of care givers. Families often work closely in partnership with such service providers, at the cost of the expressed will and preference of persons with psychosocial disabilities. It should be emphasized in the mental health context, that service providers often become custodial, gatekeep and control individuals with psychosocial disabilities. When we say equal rights of care givers and care receivers, we are handing power back to those who abused and violated our rights.

It was suggested that we should differentiate between care and support. Care is not a concept in the CRPD and the disability movement does not recognize it, preferring 'assistance' and 'support' over 'care'². There should be specific indicators on the domain of care and the domain of support and that these should not all be mixed in the same bag.



Disability assessment tools

Disability assessment tools were also discussed during the meeting. Member from Nepal gave a context of the social protection schemes in their country and the criteria set by the government for persons with disabilities. They are asked to categorize disability into severe, profound, mild and moderate. The team shared the difficulty of this system making them unsure of how to respond to this system. Washington set of questions have been used to assess disability since the last 10 years, but it has always left behind persons with psychosocial disabilities. It is also based on the medical model and not the social or human rights model. There is a need for our movement to build advocacy around this. Disability assessment needs to be streamlined and better and uniform tools need to be developed. This will also help us gain an entry into the disability door. WHODAS is based on functionality and impairment, and also has limited value, but perhaps more favourable than the Washington Set. Neither address aspects relating to discrimination and barriers, covering only individual 'deficits'.

² <https://whatweneed.tci-global.org/wp-content/uploads/2022/12/TCI-Positionality-on-Community-Inclusion-2022.pdf>

Discussion from photo story work

The Secretariat team shared the basic design and text of 'Transforming Communities for Inclusion: A photostory', drawn from the Community Inclusion Conclave organized in Pune by our member, the Bapu Trust, in April of 2023. The objective of this photostory is to provide illustrative examples (activities, processes, resources) of deep community engagement and how to establish support systems suitable for the global south.

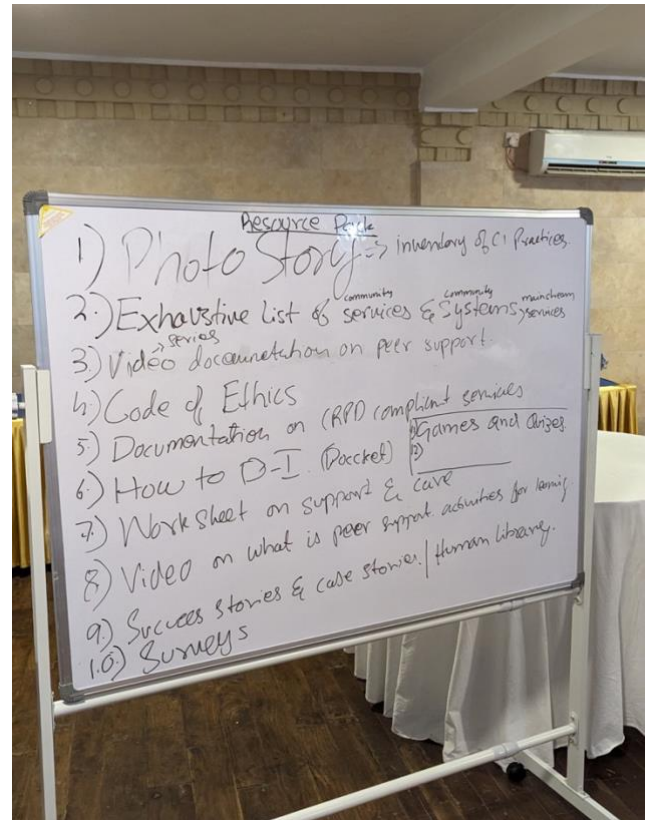
Empathy *shivir* and story telling: Also called as 'empathy collective', this can take the form of a Human Library (NCS-CAF) etc. These can be done anywhere, people come together and share stories of adversity, their experiences, their achievements, and people collectively feel those emotions. It is a powerful way of sharing common stories and experiences. As inclusion service providers, when you are a part of their story, you feel their pain and it is important to feel it. Sharing stories is a program/space in itself and it generates a lot of resilience building at the community level. Harvesting clear indicators on how the stories started and how they changed over time can be included as programmatic elements and can help to understand the impact of inclusion program in the community.

Peer support: Peer groups often fail because there is no logic or method to the programs. Or, they simply serve as a gate to enter the mental health system, directed by psychiatrists. Having a program view of the various activities we engage in is important. It helps us to approach these activities with research questions and to check the impact of each activity. Drawing and measuring indicators is one of the ways to check the impact. There is also the dilemma of whether peer support groups should have a structure or not, and if adding a number of psychosocial support activities to peer support groups increases their impact. The Intentional Peer Support program was mentioned, which is a structured peer support program.

Community justice systems: In the Global South, families and communities do not prefer approaching the courts for settling down matters. They are usually handled or managed within community set ups. Community solutions are broadly acceptable by everyone, for example, *lok nyay* (people's justice) courts in India, *Jirgah/Vadera* system in Pakistan, restorative justice systems (local community courts) in Kenya and other African countries etc. Communities deal with moral issues everyday, but they do not see them like that, such as, someone being denied food and fluid, someone being forcefully taken to the mental hospital etc. These are presented as moral issues to the community and accent is put on moral values of support for community members. Questions such as are we doing the right thing? Should this be done to any person? etc. are presented to the community members and a debate (*'panchayat'*) ensues. Community inclusion programs should work with and mobilize opinion builders in the community who hold values of the community and work together to present suitable moral solutions. For example, engaging religious leaders, key community persons etc. Such practices keep scope for collaboration and cooperation along with confrontation. It also sets an example

of how the community worked together and arrived at a solution. When punitive forms of solutions are presented (e.g. reporting to the police or legal aid authorities), people work out of fear and not willingness to change the situation, hence these collaborative approaches bode well for communities. Discussions should also be centred around if circumventing formal justice systems is also considered access to justice? Do legal problems always require legal solutions? Etc.

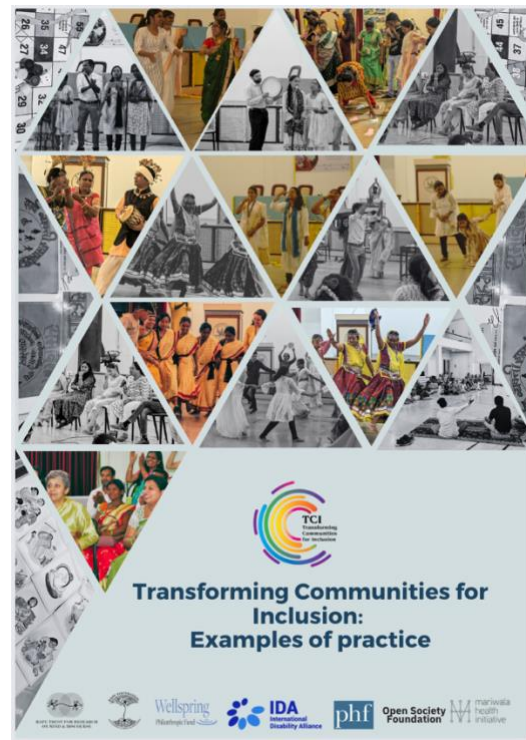
Ideas for resource pack
1. Photo Story: Inventory of CI practices
2. Exhaustive list of community support services, community support systems and mainstream services
3. Video series on peer support
4. Code of Ethics for working in the community
5. Documentation on CRPD compliant services
6. How to de-institutionalize
7. Worksheet on support and care
8. Video on what is peer support – some activities for learning
9. Success Stories and Case Stories (Human Library)
10. Surveys
11. Games and Quizzes



Creating/Raising awareness: Article 8 of the CRPD (Awareness generation) is considered as a by the way means that an organization does, to complete program objectives. However, it is one of the most important ways in which communities are transformed and strengthened. It helps to carry message of inclusion to the people and has been seen as a game changer. The various kinds of resources generated and developed would also help to influence the agenda of CI and help the donors to look at it as an independent funding strategy.

There are the dilemmas of who should inclusion programs target? Individuals or the community as a whole? Whether there are ways of influencing and changing the mindset of the whole community? Is this too difficult to do, or even impossible? However, if this is not attempted, behavioural change towards inclusion cannot happen.

Awareness messages should be centred on inclusion as opposed to the availability of medications, clinics etc. They should address prevailing stereotypes, beliefs in the community and reduce exclusion of persons with psychosocial disabilities. Their key messages can be different for different types of stakeholder groups in the community. An idea was shared on creating a resource kit on awareness strategies with key messages (CRPD, impairment, social barriers, psychosocial disability, etc.) Also, change in the language of psychosocial disabilities should be accompanied by evidence of an actual change. There should be thought given to the way psychoeducation is delivered to families. Is there a way to do psychoeducation without compartmentalizing a person as a bag of impairments or symptoms? There should be a focus on changing our own language and narrative while working with communities and persons with psychosocial disabilities. It should also be noted that if we follow the models/languages where we say there is no impairment, as are often asked the question of then why are you in the disability sector? BT then worked on finding a new language for us and started using terms like psychosocial issues, stress, psychosocial distress, disturbance etc. other than building a strong narrative on restrictions of participation and facing barriers. Persons who have endured psychosocial trauma, it stays for a long time, so there is a reality to the impairment but there is no name for it. Also the barriers are often unnamed, as they are considered as 'non persons'.



Community Inclusion machine

The facilitator of the interactive activity provoked the participants by asking, 'What kind of machine is inclusion?' It was a useful metaphor picked up by all, and they gave their voice and imagination to constructing an 'inclusion machine'.

CIC- Kenya:

Power supply: donor, social capital, legal framework, CRPD, concepts and ideologies of the movement.

Control system: efficiency and effectiveness: filtering out ambiguities; advocacy specific thematic areas; target messages;

Feedback mechanism: who is playing what role, how they affect us.

Open/closed loop: open conversations or closed, do we put it into public awareness

Amplification: share in the wider area

Output: best practice

Impact and outcome

Coding: done by OPDs because we understand the concepts, systems (CRPD is the machine language)



Koshish, Nepal

Key: issues (PSD, empowerment)

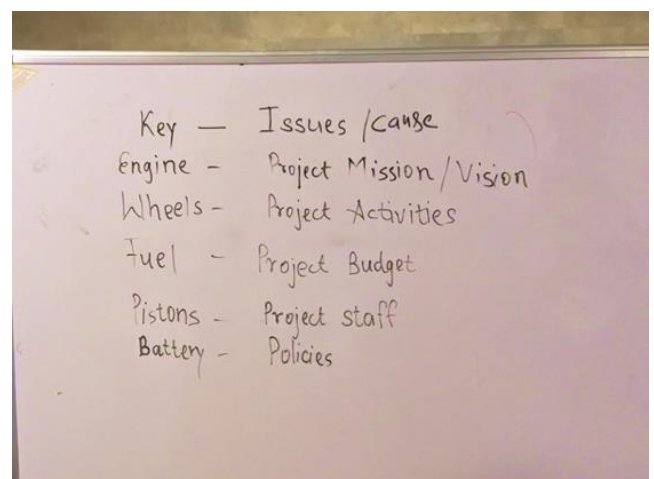
Engine: Project mission/vision

Wheels: prog activities

Fuel: Funding

Pistons: Proj staff

Batteries: Policies and laws including CRPD



TRIUMPH, Uganda

Key: Donor (DRF, TCI, IDA, CAI, PANPPD)

Engine: Planning (drafting proposal, budgeting, M&E) [Will power, empathy, stamina what builds it up that can be a part of the engine?]: Building the capacity of self advocates]

Wheels: Activities

Awareness, capacity building, inclusive clubs creative arts, advocacy, networking, economic empowerment

Fuel: Vision and Mission

Battery: CRPD

Art 25, 13,6,19

Shock absorber:

TRIUMPH Machine

KEY - Donor
DRF, TCI, IDA, CAI, PANPPD

Engine- Planning
Drafting proposal, Budgeting, through weekly meetings. Monitoring and evaluation

Wheels- Activities
Creating awareness, capacity building, inclusive clubs, Creative arts, Advocacy, networking, economic empowerment.

Fuel – Vision and Mission
Our Vision: “Society that fully includes persons with psychosocial disabilities”.
Our Mission: To contribute to the process of enhancing recovery, building resilience and investing in social networks for inclusion of persons with psychosocial disabilities.

Battery- CRPD

Battery- CRPD
Art 25 Health
Article 13
Art 6
art 19

Shock Absorbers- Risk assessment
Safe guarding policies
Child protection policy
health services

LAT, Thailand

Community inclusion Machine

Key Donor Empowering persons with Disability Fund

Engine *planning* therapists, clients, community, venue, resources, funding, pre-assessment, *monitoring* -consultations during the course of 10 sessions, and *evaluation*- post assessment of the wellbeing and relationship with people in contact.

Wheels Activities Art therapy

Fuel vision- persons with psychosocial disability can have well-being, related well within and without

Mission -support persons with psychosocial challenge in their journey within and interaction without through art therapy

Pistons Staff -staff at living association-training team

Buffer CRPD translated into routine interactions and culture of the group

Shock absorber Risk assessment How?

Community Inclusion Indicators Workbook

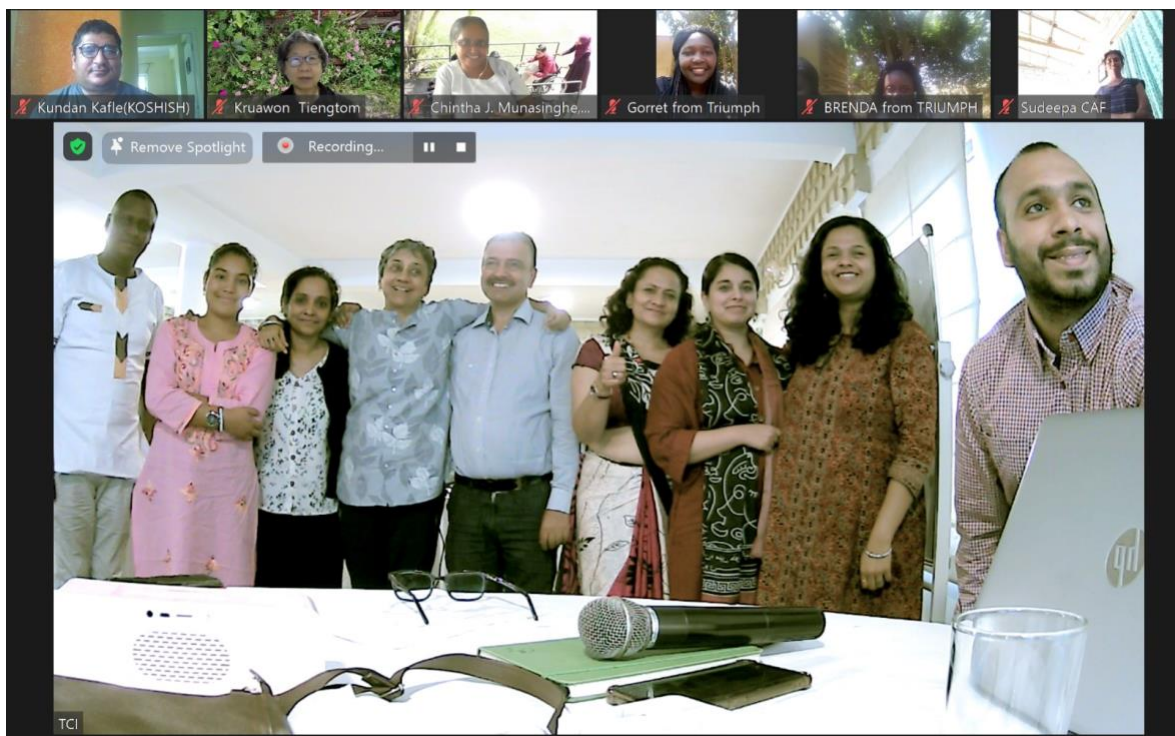
About the indicators: Community Inclusion is not just a philosophy; it is a practical concept. Indicators will help in providing output on what inclusion exactly means and every small action that triggers a thought on being included in the community can be counted. The practical

indicators can be gathered from the field and this information flow can be integrated along with developing action plan. The indicators help us in naming the work organizations have been doing in their communities and aid in showing that inclusion is possible along with rethinking strategy. The indicators along with the resource pack can be a potent combination. The use of indicators can give an idea on what program aspects need to be strengthened, held in internal reflections for the organization, to be able to plan well and lay out a pathway. There is also scope to expand the current list of indicators, developed by TCI from BT experiences. Indicators also help organizations to stay on the CRPD platform and stick to their boundaries. This avoids organizations' moral policing of their communities.

The WG-CI members discussed the various type of indicators that could be developed to measure and monitor the various inclusion programs in communities.

Discussion around training topics

The WGCI members discussed the various training topics they would want to cover in a training programme and some ideas were generated in that regard.



Transforming Communities for Inclusion

Transforming Communities for Inclusion (TCI) is a global Organisation of persons with psychosocial disabilities [an OPD]. TCI forecasts a future in which all human rights and full freedoms of persons with psychosocial disabilities are realized. We are guided by the United Nations Convention on the Rights of persons with Disabilities (UNCRPD).



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