Civil Society Forum under the auspices of the 16th Session of the Conference of States Parties to the UN CRPD
12 June 2023 | 10am to 2pm
Conf. Room 4, United Nations Headquarters, New York

Moderator: Jose Viera

Q1: What have we achieved? 5 minutes each speaker

Bhargavi, the **DI guidelines** has been a significant milestone. Could you tell us about its implications for the disability movement at large and its implications on **community inclusion**, especially for persons from underrepresented groups. **5 minutes**

The CRPD committee adopted the 'Guidelines on De-institutionalization, including during emergencies' in October last year. The DI Guidelines while not creating any new propositions for human rights, elaborates on a reading of the CRPD on the topic of institutionalization.

There has been a debate whether the CRPD prohibits institutionalization. The Guidelines draws unambiguous conclusions on this, adding to GC 5. It says that disability-based institutionalization is a discriminatory act of violence, a de facto denial of legal capacity and a prohibited form of deprivation of liberty. It is not by choice that people live inside institutions, though they may get used to it. Governments should not invest anymore in institutions, and must dismantle those that exist.

The Guidelines gives a very practical, step by step inventory of policy and program actions to take, for governments. The map of actionable described should encourage governments to go forward, without delay.

Some persons with disabilities, e.g., mental, intellectual, multiple, psychosocial disabilities, children, those persons on the gender spectrum and elderly, migrants, are disproportionately found within institutions. Structural discrimination on all persons with disabilities being quite high, all persons with disabilities, indeed, are at risk for institutionalization over their life span. They have the right, without discrimination, to live uninterrupted lives in the community, on equal basis with others. The Guidelines provides a vision and process for this.

Policy makers can view the policy agenda for inclusion as restricted to the resettlement of institutionalized persons in the communities. Actions on resettlement alone will not result automatically in Community Inclusion. For effecting community inclusion, investments must flow directly into communities, effecting social, behavioural change in neighbourhoods, transforming them for inclusion. And, this must happen without delay. An interesting consideration is to see, if programs implement the solutions listed already in the DI guidelines on community inclusion, can it result in our not needing those institutions? If there are already innumerable programs implementing country and context adapted community inclusion programs, will communities still admit their relatives in these institutions?

DI is a specific set of policy actions for institutionalized persons, with a core set of program ideas on community inclusion suited for persons leaving institutions. Whereas, community inclusion is more encompassing, is wider strategy and has a broader vision for the inclusion

of all persons with disabilities. It is looking at communities as a resource for mutual support, availability of relationships and resources, social capital, availability of all necessary mainstream resources and services, availability of disability specific services and an overall inclusive psychosocial ecosystem, supporting peaceful and just communities. Investing in Community Inclusion as an independent stream of works, inclusive of a strong core component of de-institutionalization, is the larger package policy makers must aim for.

Agencies working on community inclusion must draw from the DI guidelines as a new reference point. Donor, bi-lateral agencies must consider community inclusion as an independent stream of funding. An inclusive community is not only for persons leaving institutions, not only for persons with disabilities, but it is for all persons.

Q2: Who was left behind and why? – 5 minutes each speaker

- **Bhargavi**, did the SDGs leave persons with psychosocial disabilities behind? What are your thoughts? **5 minutes**

Yes, indeed, we are still bound, after 15 or more years of the CRPD by a 'legal shackling'. Physical chains are somewhat easy to break, but the laws- mental health laws and incapacity laws- that binds persons of unsound mind, persons deemed to be mentally ill, are intractable. Some countries still have held on to reservations on Article 12. Professional lobbies managing institutions have the highest legal normative power to sequester us into this shackling. Lives are spent exhausting ourselves in fighting this impossible system, where epistemic injustice is very high: our stories, knowledge, our personal practices, ways of life, everything is extinguished before this system, as we are stripped of our personhood and all resources that are needed to live a decent life of our own making, and the risk of violence is extreme.

Under these circumstances, dear Jose, it is impossible to make an entry into the SDGs scenario. We are not even at the door. Getting domiciliary status, a national card, opening a bank account, a disability card, any pensions, owning anything of our own, and establishing our status as a citizen- every aspect of life is a struggle.

Recently, in the high-level political circles influencing the UN, there are advanced proposals to allow the 'mental health agenda' to take over and subsume the SDGs agenda. The resolution presently negotiated here in NY proposes to bring 'mental health' into each and every SDG, its goals and targets. This will spell a human rights disaster for all persons with disabilities, and indeed all persons on the planet. Not only persons with psychosocial disabilities, but all persons with disabilities will be slowly medicalized and sweeped into 'mental health care' with this subversion. From our point of view, we yearn for a 'mental health free' space where we can still hope for social justice to be restored. This space is the SDGs. If applied in all aspects of human life, under the same conditions of 'mental health care' as now, we can be sure of the capture and control of persons identified with 'mental health conditions' in *all potential SDG catchment areas*, and to treat them against their will. We express grave concerns about this resolution.

This is not to say that 'mental health' is not important. Organizations we work with have been evolving holistic support programs by changing the entry point from 'mental health' to

'inclusion', not engaging with 'treating mental disorders' but with providing housing, employment, social protection, completing education, other than specific psychosocial services including creating support groups, offering peer support, trauma informed support, having 'listening or storying hubs', arts-based support and enabling violence free environments. Psychosocial health and wellbeing belong in the social sector, and should be realigned with social knowledge, values, skills, curricula and practices.

Q3: Where should we be ringing the alarm bells? – 5 minutes each speaker

- Onto our last question: here, we ask: what are some of the **issues that will continue to play out** for persons with disabilities?

- Time and time again, international crises have shown us how easily our human rights can be cast aside. We saw this during the COVID-19 pandemic, where our communities were hit hard. When conflict hits, everyone rushes to move to safe areas ensuring the security and health for themselves and their family members. But for many persons with disabilities this is not possible. Evacuation plans are often not designed in accessible ways.

- Bhargavi, in your communities, can you tell us about some of the issues that continue to play out for persons with psychosocial disabilities? You touched on some points in the previous part, so <*Jose to ask follow up question*>**5 minutes**

Other than the intractable legal issues and being left out of the SDGs? Well… hmmm…??

You have mentioned crisis and conflict, humanitarian emergencies. We have heard reporting from several members across regions where we work, in the global south, about people being abandoned inside of institutions in such times. In urban areas, where poverty is rampant, during the pandemic, people desperately needed access to a phone and a data plan. We must indeed raise concerns about the almost routine forced medical treatments, and including non-consensual sterilization, hysterectomies and adoptions that are inflicted women with mental, intellectual, multiple and psychosocial disabilities. The medicalization of experiences of people on the gender spectrum, LGBTQI+ and the terrible human rights violations happening there in the name of 'treatment of mental disorder' is being highlighted in our communities these days. As emerging from several considerations before the CAT, we hope that several of these practices will be clearly defined as 'torture'. I will like to leave off with a great lesson TCI learnt in supporting the Committee in drafting the DI Guidelines, with members of the Global Coalition of De-institutionalization, is to view the whole matter of institutionalization as a matter subject to a reparation's perspective. In this context, TCI honours our leaders and martyr's past, present and future, giving their lives to expose the harms caused by old laws and policies allowing disability-based incarceration. This view recognizes institutionalized persons as survivors and as victims of historical oppression.