**Written Submission on Draft Guidelines on Deinstitutionalization, Including in Emergencies**

28-06-2022

To,

The Committee on the Rights of Persons with Disabilities (CRPD)

Human Rights Treaties Division (HRTD)

Office of the United Nations High Commissioner for Human Rights (OHCHR)

Palais Wilson - 52, rue des Pâquis

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Sub: Written Submission on Draft Guidelines on Deinstitutionalization, Including in Emergencies

We wholeheartedly welcome the Committee’s initiative to frame draft guidelines on deinstitutionalization to support the right of persons with disabilities to live independently and be included in the community. As an organization of persons with disabilities we submit herewith our comments on key paragraphs of the draft guidelines.

Best Regards,

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Bapu Trust For Research On Mind and Discourse[[1]](#footnote-1) is an organization of persons with disabilities, working in low-income communities of Pune city, India.

We have been delighted to receive news on the efforts taken by Global Coalition for Deinstitutionalization (GCDI), supporting the work of the Working Group of the CRPD committee in developing Guidelines on Deinstitutionalization, including during emergencies. This draft holds the promise and vision for a liberal and free spirited understanding and translation of inclusion of persons with disabilities, including persons with psychosocial disabilities, globally.

We wholeheartedly support the said guidelines in implementing Deinstitutionalization in spirit, word and action. Deinstitutionalization and prevention of Institutionalization holds the promising vision of a world many of us dream of. We strongly support the work of the Committee in ushering this movement and change.

As an organization of persons with disabilities we submit herewith our comments on key paragraphs of the draft guidelines.

**II.**

We strongly agree that State parties have a duty to end Institutionalization.

Suggested addition: **II.9**

State parties have an obligation to end all forms of Institutionalization with immediate effect and put into course a detailed time bound action plan for implementing this. Inclusion into communities should be an important outcome of the de-institutionalization process.

Suggested addition: **II.11**

Institutions should not be an option as it violates Article 19 of the Convention. Families resort to institutionalizing the person in private and public spheres, due to the absence of responsive community support systems. State parties should ensure availability and access to community based programs working from the disability inclusive development framework to end this.

**III.**

We strongly agree that discharge from the institution and transitioning to open communities is process oriented and has to be well conceived.

Suggested addition: **III.21**

Community based support systems and services should be participatory, engender choice, autonomy and dignity of the person. The person has the primary and active say in all matters concerning them at all points of time.

Suggested addition: **III.23**

Inclusion of persons with psychosocial disabilities should be the outcome of all community based mental health programs. Support services for independent living should be built on the foundations of zero coercion, keeping the right to consent and choice at the core of all actions. An exit plan should be in place to enable people to move from an institutional setting into communities of their choice through linkage with such a community mental health and inclusion program. To further this outcome, communities have to be prepared to receive and include people who have lived in institutions. The existence of such a program is a precondition to facilitate, further and advance the outcome of deinstitutionalization.

Suggested addition: **III.29**

The government should provide financial and infrastructure support to run community based field programs. Funding of institutions should be replaced and reinvested into such programs, in a time bound manner.

**V.**

We strongly agree that State parties have an obligation to enable legal and policy frameworks to end Institutionalization.

**Comment:**

Unnecessary paperwork, postponing timelines, pushing decision-making and action, administration delays and having to meet multiple people multiple times for the simplest of approvals leads to delay in justice for persons within the institution.

Suggested addition: **V.51**

Negotiating with the system is the singular most barrier to enabling Deinstitutionalization and in prevention of institutionalization. Legal in-capacity laws set up multiple barriers, for the person, to exit from the institution. Deeply embedded institutional culture, attitudinal barriers, procedural delays, gate-keeping at every step, rigid bureaucratic processes, excessive regulations are barriers experienced by persons with disabilities, especially those with intellectual and psychosocial disabilities. State parties should take proactive steps in dismantling the institutional culture across all levels.

Suggested addition: **V.i.53**

Laws or clauses that do not fully comply with the convention are roadblocks to the implementation of Deinstitutionalization. Such laws should be discontinued with immediate effect, paving the way for legal harmonization for implementing Deinstitutionalization.

**V.iv.57**

**Comment:**

Access to housing, education, livelihood, holding contracts and property, entering into rent agreements for independent housing, opening of bank accounts etc require the person to have valid photo identity cards and citizenship documents. The documents cannot be facilitated for many persons leaving the institution due to the absence of historical data sources or papers: e.g. place of residence, proof of residence, school or college certificates etc.

When this happens, the person’s options to full participation get stuck despite coming out of the institutional set up. This severely limits opportunities to the person when they step out. The situation of the institutionalized person is akin to homeless people. The outcome of Deinstitutionalization thus cannot be implemented unless systems and levels of the government are responsive in the removal of these barriers.

The system is riddled with such gaps seriously impacting the person’s prospects for growth and development. Full and effective participation is not possible in these contexts.

Government systems and duty bearers have a duty to act proactively in addressing, resolving and removing these barriers.

**V. c. 66**

We strongly agree that the emphasis on processes, systems and procedures to implement and expedite Deinstitutionalization are as important as implementing Deinstitutionalization.

Thus making the right real for all persons with disabilities, including persons with intellectual and psychosocial disabilities.

**Comment:**

Discharge from the institution and transitioning to open communities is process oriented. Vast and diverse development partnerships make Deinstitutionalization possible, with the outcome of inclusion; and; within community based programs. (E.g. partnering for housing, livelihood, government schemes, social protection and vocational training)

**VI.**

We strongly agree that availability, accessibility, acceptability, affordability and adaptability of community based support systems are a prerequisite to enabling and implementing Deinstitutionalization.

Suggested addition: **VI.**

Community based programs including community mental health programs should offer many strategies to prevent institutionalization. The program should offer an expansive array of formal and informal networks, support systems, independent living assistance through development partnerships and peer support networks to create inclusive communities. This kind of program design is imperative to make Deinstitutionalization real for all persons with psychosocial disabilities.

The community based support programs should have many kinds of services and many kinds of stakeholder partnerships. This will enable creation of conducive conditions for implementing Deinstitutionalization.

**Comment:**

(Esp. in context of person's with high support needs)

The benefits of a community mental health program working from the disability inclusive development framework make it possible to implement Deinstitutionalization. E.g. Linkages with governmental and non-governmental development schemes and services, open dialogues with families, intensive work with neighborhoods to create circles of care, relationships with neighbors, peers, friends, family, access to peer groups, service providers from local communities, linkages to different kinds of service providers, supported decision making, trauma informed support, community led approaches, drug withdrawal strategies etc.

Exhaustive lists of daily micro actions in the field are required. Offering a variety of social opportunities to the person based on their express preferences, building the person's social capital and a community ecosystem to support the person to be a part of the community fabric prevents institutionalization and enables deinstitutionalization.

**VI.b.80**

We strongly agree that support systems and services should enable all persons with disabilities, including children with disabilities to realize their full potential.

Suggested addition: **VI.b.80**

Support services or persons should not go with the assumption that they know what the person needs or wants. Community belonging and inclusion is an on-going process for persons leaving the institution and is different for each as they make their own decisions and life choices.

**VI.e.87**

We strongly agree that some persons and families with high needs for support will require general income support as well as disability specific support costs.

**Comment:**

When the person steps out, they do not have social or economic support systems outside. It is difficult to access government offered social protection measures immediately on discharge from the institution. In addition, identity and citizenship documents are required for accessing any of these schemes. The person may require some temporary measures to cover expenses till a sustainable alternative is available to the person. This was enabled through offering social protection measures in the form of a cash policy to the person. Over a period of time community support structures and partnerships can be cultivated around the person and/or the family to take some of these costs through cost sharing or as other sources contributions- for e.g. stepping in as volunteer personal assistants, providing appliances, support through disability specific schemes etc.

Transitory livelihood options are possible within low income community settings, through partnerships. Employment in the local communities and vocational training opportunities are possible through intersectoral collaborations. Opportunities to re-skilling can be provided in the community based program (e.g. structuring the day, handling money, moving about independently, and doing small assignments to cultivate the habit of working, being in a simulated work space environment, taking rest breaks etc).

**Challenge:**

Setting up sustainable livelihoods is challenging. Loss of skills due to institutionalization, numbing effects of medications, unavailability of education and identity documents, are serious barriers in this context.

**VII.a.93**

We strongly agree that persons leaving institutions should be provided with support to prepare for community life. In parallel, preparing the community to receive the persons should be done intensively, under community based programs.

Suggested addition: **VII.a.93**

Given the needs for gradual transition from living within closed institutions to open communities, multiple pathways should be developed in response to the person's expressed needs as they prepare to move out from the institution. A wide assortment of support tools should be offered to do this.

**Comment:**

Offering support interventions aimed for acquiring skills for independent living, from within a dependence driven system are cornerstones to realizing the outcome of inclusion. E.g. Alternative and Augmentative forms of communication using expressive arts, providing various options for residential arrangements, facilitating gradual re-introduction to open, community and social spaces, and spaces outside of the institution etc.

1. <https://baputrust.com/> [↑](#footnote-ref-1)