Centre for Global Disability Research, The Critical Institute, Malta

**The Critical Institute Submission with comments to the CRPD Committee’s draft general comment no. 5 on living independently and being included in the Community**

INTRODUCTION:

The Critical Institute is a non-profit organisation set up and run by academics and activist practitioners. It offers a democratic and interdisciplinary platform to debate, learn and collaborate on world class critical research, teaching and practice. We engage in practice that actively questions and confronts inequalities and oppression- knowledge and practice that have a transformative agenda. The Centre for Global Disability Research (CGDR) is an active and dedicated centre for research and teaching on all aspects of the disability experience, with a special focus on the global South. Our work engages world class researchers, academics and activists, with a view to influencing policy, professionals and organisations (national and international) to think critically about disability in the global South, improve practice, and challenge disablism.

The Critical Institute welcomes the opportunity provided by the CRPD Committee to submit comments to its draft general comment no. 5 on living independently and being included in the community. We highly encourage the CRPD Committee to take into consideration the following arguments relating to para 47 of its draft general comment, particularly to consider the context in which persons with disabilities might choose to live within institutional care settings, such as: the non existence of support services or its non- affordability due to lack of governmental compliance; non existence of family, social or community links due to the person having lived within an institution for extended periods of time; poverty conditions, particularly for those living in the global South; among other reasons.

It is indeed a positive way forward to offer the possibility of institutions as location of residence when these facilities are indeed chosen and demanded by persons with disabilities themselves. This paragraph is progressive in emphasizing the ‘right to choose’, and to include here the much maligned institutions. It is, though, imperative to contextualize a statement such as this, and why institutions may in certain instances be the only possibility available. This is important to not demonize institutions in the same way that medicalisation has been by disability and other activists with radical positions:

* It is indeed easy and perhaps logical for privileged persons with a disability in the global North and South to reject medicalisation and institutionalization when they themselves have access to quality medical care and community based services and family support. It works counteractively in low income and poor contexts, especially those living in extreme chronic poverty who struggle to cater for food and the most basic of health care, let alone specialized health care whether on account of extreme poverty, remoteness, transportation barriers or a combination of these. At the very least, it dilutes and weakens the demands of disability and other activists lobbying for more and safer health care services, government commitment and resources, and adequate monitoring of these services. It also ostracizes professionals from engaging, learning about, and including persons with disabilities. These can be medical doctors, psychiatrists or physiotherapists among others. Even innovative and progressive ideologies and practices such as Community Based Rehabilitation (CBR) are dependent on critical linkages and connections with medical services and institutions.
* In contexts of extreme poverty such as Central America, families on the brink of hunger, living in isolation, with no services and no basic needs and with a family member with severe intellectual impairment, struggle to put food on their table, to cater for health care needs, to plainly survive. Disability impacts all family members including children, sometimes forced into laboring prematurely to make up for the lost labour of the person with a disability, cater for the fragmented health care costs and so on. Sometimes, families themselves may choose institutionalization as the best option, not out of neglect or lack of love and care, but as a means to at least enable the survival of the person with a disability. People may choose this as a form of personal safety, for example those in isolated communities subject to sexual violence and abuse.
* Related to the above, persons with disabilities may indeed choose institutionalization as a way of bettering their quality of life, access support, and in extreme cases, to survival. This may be the case for example with elderly persons with disabilities, who like non-disabled older adults may choose to be insititutionalised. It is indeed imposing to remove the option from being there.
* It is problematic to do away with institutions without offering an alternative or even a strategy for deinstitutionalization and well-resourced community-based alternatives. While we are aware of and sensitive to the extreme rights violations and violence that do happen within many institutions, putting people on the streets, with no food, no care etc. will constitute more violence. Many, such as those with mental health problems hailing from distant rural areas, interned in the Guatemala city’s institutions, have nowhere to go to. They are in the most extreme poverty, have no money to depend on, and also no care. A substantial number have been abandoned by their families and do not know how to go back home and do not have the means to do so.
* Related to the above, the extreme posture towards government run institutions may indeed serve as an incentive to divest themselves of providing any services at all. In low income countries, governments on extreme neoliberal trails and even corruption, already do not even provide the bare minimum to ensure basic dignified care and survival. Governments everywhere may well latch on to anything to rid themselves of any form of social responsibility and care- persons with disabilities as we well know, are too often pitched as burdens or an economic cost by governments.
* There is lack of clarity on what is understood by ‘institutions’ and ‘institutionalization’ in the text. Not all institutions and institutional care violate human rights, and not all are a source of oppression. There are alternative arrangements where a group of persons with disabilities may indeed choose to live together in a variation of alternative care. This may include homes for older adults. There are also community based homes backed by government support and care- this support is still institutionalized, and people with disabilities are still accountable to at least some government conditions, including the lack of personal choice as to who provides the care. Premises are also not owned by persons with disabilities.
* Not all institutions are run by government. There are many that are run by NGOs, provide adequate and dignified care. Tarnishing all with the same brush runs the risk of staving off critical services while offering no real alternatives.

1. Proposed text of the amendment for para 47:

The right to decide where, how and with whom to reside, also embraces the individual’s decision to live in institutional care settings, because there is no obligation to live under a particular living arrangement. However, as article 19 of the Convention is about being included in the community, adequate efforts and resources should be devoted to offering well-resourced, quality and dignified community based services that are adapted and responsive to context, cultures and ideologies, and personal requirements and demands. This, though, needs to be done progressively and strategically and backed by adequate resources and commitments from all concerned stakeholders. It, though, does not exempt States Parties from maintaining existing institutions in the interim in the highest and safest standards and to seek alternatives that in no way compromise the well-being and safety of persons with disabilities.

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