



‘Support’ as ‘Care’

A/HRC/52/52 (advanced unedited version) report from the OHCHR¹

A response from TCI

A report from OHCHR, viz. A/HRC/52/52 ‘Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic’, was released early this year. TCI has focussed interest on CRPD Article 19, the Right to Live Independently and be Included in the Community, including community support systems and services and building inclusive communities as the way forward, after the corona virus disease pandemic. Our interest is both in any evolving elaboration or jurisprudence around it, but also how this article may inspire communities towards inclusion. Hence our name, ‘Transforming communities for Inclusion’.

A report on ‘Support Systems to ensure the Community Inclusion of persons with disabilities, including as a means of building forward better after the pandemic’ is deeply appreciated. We greatly welcome this mandate provided by the HRC. With this mandate, communities and stakeholders will be well advised on the practical ways of implementing the CRPD, along with other development instruments such as the SDGs.

TCI was a partner to the initiative of GCDI (Global coalition on De-institutionalization), which supported the work of the CRPD Committee on bringing out the ‘Guidelines on DI, including during emergencies’. TCI was very happy to have contributed to this process, and celebrated the final receipt of a very comprehensive and practical guidance. We anticipate and would be greatly encouraged by further reports on community inclusion as such a set of reports, guidances, resolutions, etc. *which are CRPD compliant*. This would go a long way to support, supplement and embellish the DI Guidelines.

However, we express our concerns here, that this report A/HRC/52/52 does not fulfil the noble mandate of the OHCHR, is not compliant with the CRPD nor does it advance our advocacy on community inclusion. More concerning is the fact that it serves the interests of service providers, particularly health (and mental) health care providers, who have always compromised our wellbeing and practiced violence upon our constituency over decades. TCI is the largest representative voice of persons with psychosocial disabilities, with membership base in 50 countries. *We were not consulted on this report.*

¹ A/HRC/52/52 ‘Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic’. Advanced Edited Version, adopted in the 52nd Session of the Human Rights Council.

The CRPD is not about ‘care’

The word ‘care’ does not occur in the text of the Convention except in a few places. It occurs in articles 18.2, 23 in the context of families which do not ‘care’ for a child with disabilities. It occurs in 25 in the context of laying out the conditions for human rights-based health ‘care’ and other ‘care’ services. Here, it is used as a generic descriptor of services. It can be stated that ‘care’ is not a concept that is linked to any human right in the CRPD. It does not even occur in places where one may expect it to – for example 7, on children with disabilities or Article 19; Nor, importantly, as a legal piece of caution conditioning or qualifying provision of support for persons with disabilities *vis a viz* caregivers or service providers. Where it occurs, the concept comes in, in an everyday way not subjected to any kind of specific legal interpretation.

In TCI, we have not heard of any dialogue, debate, elaboration, interpretation or jurisprudence on ‘care’ in the context of CRPD rights and persons with disabilities. Indeed, the tensions of using ‘care’ in this context has been in the forefront of disability rights discourse and has been rejected in favour of ‘support systems and services’ – the very essence of Article 19.2. There are no rights related to ‘care’ within the scope of the CRPD, neither for the care giver, nor for the care receiver, as the concept of ‘care’ is null and void within the scope of the CRPD and the disability rights discourse. This reasoning by TCI cancels the very rationale of this report, as it exists.

Infact, in the drafting of the CRPD, and in the jurisprudence thereafter, there was never any doubt that the Convention is about the centrality of disability rights and playing the interests game between the person with a disability, their communities and their care providers was set aside, as undermining the voices, experiences and the rights of persons with disabilities.

The mandate is not about ‘care’

The document A/HRC/52/52 was developed in response to HRC Resolution 49/12. ‘In its resolution 49/12, the Human Rights Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to prepare a thematic study on support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic; and a subsequent study on good practices of support systems enabling community inclusion of persons with disabilities’. This mandate, in its description, does not mention the concept of ‘care’, centering community systems that will support and assist persons with disabilities realize their right to live independently and be included in communities. However, A/HRC/52/52 while having the mandate of reporting on ‘community support systems to ensure the inclusion of persons with disabilities, has turned the wheel backwards, towards the ‘care’ concept, starting to define the rights domain afresh, which is not a part of the mandate of this Resolution. It is not acceptable that a mandate, participatorily developed with the participation of the disability rights movement, built on the 15 years of CRPD intelligence, turn the question of support, found in nearly all articles of the CRPD, to ‘rethinking care systems’, ‘problematizing traditional care models’, or arriving at a ‘support approach to care’ (an incoherent mix of concepts). Concepts used in the CRPD have been ‘accommodations’, ‘assistance’ and ‘support’. By now it is an *a priori* that the text of the CRPD resonates in almost every article, with guidance on ‘support’. The DI Guidelines provides exhaustive inventories on policy and legal actions to be taken, to build up circles of care, support systems and services, as well as enabling persons with disabilities to access mainstream services on equal basis with others.

There is no new stream of human rights

The report proposes a new stream of rights ‘the right to provide care’, ‘the right to receive care’ and the ‘right to self-care’. There is absolutely no scope of interpreting the human rights narratives, including of the CRPD- at any point in the history, genesis or evolution of its jurisprudence, to justify that a human rights based approach to disability inclusion should ‘*protect equally the rights of those receiving and providing care....*’. It is the dismal failure of care systems and policies that led to the right to support in all aspects of life, including the legal aspects. We need not reinvent this debate, taking us 20 years back, when such debates were ongoing in the drafting of the Convention, with a push from different kinds of governments and service providers. The voices of the international disability caucus prevailed. TCI is concerned that the years of work and struggles by the disability rights movement and the movement of persons with psychosocial disabilities would be compromised, diluted and diminished if ‘governmentality’ and a service provider perspective is brought in to run amok within the arena of human rights, very specifically built around the centrality of voices, will and preferences of persons with disabilities. Persons with psychosocial disabilities have been subjected historically to all forms of violence, including custodial violence, from care providers.

While the mandate was to produce excellent reports on support systems, with good practices and all, the report sets up an old dynamic in its place: The philosophical debate on the ethics of rights versus the ethics of care is at least 3 decades old, if not older. The women’s movement and other eminent philosophers, particularly Martha Nussbaum, have brought forward ideas that cut through the polarization between care and rights. This report does not enlighten us working from within the disability rights movement, how this debate has been resolved in a CRPD compliant way nor indeed, in any practical way impacting on the ground, lives and liberties of persons with disabilities.

Paternalism and governmentality in the proposed ‘care agenda’

TCI, in responding with censure, to this report, confirms that with the changed objectives set out at the beginning of the report, the very entry of the concept of care, its privileged juxtaposition against support, the mixing of interests between ‘care giver and the care receiver’, applying the law of averages to a decidedly disability focused human rights discourse, the document has brought in elements of paternalism, the huge risk of majoritarianism, governmentality and succumbing to service provider interests, diminishing the voices of persons with disabilities, throughout the text. When service provider rights are brought in, without any acknowledgement of the harm caused by them, alongwith will enter all the impunity clauses, ‘best interest’ and ‘least harm’ arguments and practices. Considering the decades of violence by public and private service providers, particularly institution based ones, against persons with psychosocial disabilities, this particular formulation on ‘care’ is fearful and intimidating.

The report notes that ‘Care is relational’ and that ‘the rights of caregivers and care receivers are inextricably linked’. There is a cost of care issue that the report addresses quite comprehensively, bringing the topic of care within labour laws and economic rights. However, states parties have not been disability inclusive in health care and social care services- not spending enough, not creating support services, not having accessibility features, not having disability specific health care services, use of force in nearly all aspects of specific disability health services, etc. etc. The report is considering only the part of out of pocket family expenses and invisible labour of care.

The CRPD exists in order to protect against the whimsical nature of ‘care’ and the vicissitudes of receiving support in ‘relational’ contexts: The social environment around a person with a disability, including families, extended families and neighbourhoods, is often uncaring, inhuman, the economic

and other reasons notwithstanding. The 'care' services end up providing substandard, inhuman, cruel and torturous treatments, including forced treatments and institutionalization, especially for persons with mental, intellectual and psychosocial disabilities. Surprisingly, the report makes no mention of the 'care' services, the political economy of such services, privatisation of care and the human rights violations perpetrated by them. The power asymmetry between care providers and care receivers, and the biomedical dominance has been the focus of several UN reports, particularly by leaving Special rapporteurs (Disabilities and Health) and 2 Mental health and human rights resolutions. Therefore to say that '*A rights-based approach ... is needed to harmonize multiple perspectives*' is not acceptable, as the CRPD exists to remedy this power imbalance; and not to '*structure the co-responsibilities that respects the rights of all those involved*'. To take this approach of averaging out human rights has proved to be deleterious to the health and well being of persons with mental, intellectual, multiple and psychosocial disabilities, as care providers have, in the name of 'harmonizing multiple perspectives' since long, silenced our interests and our voices by devising a variety of attributions of incapacity, acting as our proxies, guardians and institutional perpetrators of violence.

Article 4.3 was not adhered to in the drafting of A/HRC/52/52

The report is quite sparse in its use of extant UN and other available resources on support systems. The 'Guidelines on De-institutionalization, including during emergencies' adopted last year, with very elaborate guidance on community support systems and services, has not been referenced, nor the many documents pertaining to mental health and human rights resolutions, SR reports, etc. Various OPD and INGO reports on community inclusion, such as by the International Disability Alliance, Inclusion International, ENIL, among others, have not been referenced. There has been no culture of participation(Article 4.3) in the making of this report, despite the specific mandate on consultations with primary rights holders. Transforming Communities for Inclusion (TCI), the largest representative voice of persons with psychosocial disabilities with members in over 50 countries was not aware, nor invited, into this process.

We understand that this is the first step in a long process, going forwards, so it is possible to bring the initiative back on track, with the full and effective participation of OPDs.

Thank you!

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