Ghent, 04/07/2022

To: 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 CH-1201 Geneva Switzerland

Subject: Submission on “Draft Guidelines on Deinstitutionalization, including in emergencies”

Dear,

With this letter we would like to deliver our feedback on the “Draft Guidelines on Deinstitutionalization, including in emergencies” as they stand now. As colleagues – associated with the recently established Academic Workplace De-Institutionalization, part of the department Social Work & Social Pedagogy at Ghent University – we do this by focusing on deinstitutionalization as well as reflecting on this topic from a Social Work perspective. In building our reflections we will, as asked in the call mentioned, refer to the relevant paragraph even though not referring to them chronologically.

Yours faithfully,

Dries CAUTREELS Dr. Toon BENOOT

PhD student Post-doctoral researcher

Ghent University Ghent University

Dept. Social Work & Social Pedagogy Dept. Social Work & Social Pedagogy

Prof. Dr. Griet ROETS Prof. Dr. Rudi ROOSE

Professor Professor

Ghent University Ghent University

Dept. Social Work & Social Pedagogy Dept. Social Work & Social Pedagogy

https://[www.ugent.be/pp/swsp/en](http://www.ugent.be/pp/swsp/en)

Correspondence to: dries.cautreels@ugent.be

Introduction

The aim of striving towards deinstitutionalization is a goal we fully endorse, at least when this endeavor is carried out in a proper and substantiated way. Avoiding “arbitrary detention and deprivation of liberty on the basis of impairment”, “forced medical intervention with psychotropic medications” and “other interventions without the free, prior, informed consent” (cfr. Para 6) is an obviousness itself and seems to be the absolute minimum we should aim for. However, we observe some questionable statements and ambiguities in the Convention as to 1) the bandwidth used, 2) the definition used and 3) some of the key elements set out in the text.

1. The bandwidth used

The description of deinstitutionalization (Para 14) covers a wide scope – from “social care institutions” to “leprosy colonies” – and thus includes a wide variety of institutional initiatives as well as diverse historical contexts. By doing so, the objectives described seem very recognizable to several practices but, on the other hand, seem to be restricting to the wide variety one can observe in the support practices for people with disabilities. After all, small scale initiatives (even when support services are shared) are very different compared to other practices mentioned in the text. Thus, we state that the proposed Convention does not do justice to the diversity that can be seen in support initiatives, historical evolutions in diverse welfare states and legislative initiatives by striving for a comprehensive description of disability care services. It is therefore difficult to embrace the presupposed universality. The statement concerning the harmful effects of institutionalized care – in various settings and services

– does not refer to all mentioned settings and practices, we believe. So, by aiming to cover all practices we believe the universality as well as the strength of the proposed Convention is undermined. Our plea is to look at (de-) institutionalisation from a more diverse angle and hereby include a socio-spatial perspective in which not only ‘location’ is the focus of deinstitutionalization (see infra).

1. The definition used

The definition of deinstitutionalization is too narrow to embrace the diversity of care and support services and practices and, more importantly, to realize deinstitutionalization to its full extent. E.g., in Para 19 and Para 26, by excluding from the definition “community-based services” resp. “residential institutions of all kind” and “group housing – including small group homes-, sheltered workshops, institutions for providing respite care, transit homes, day care centres”, deinstitutionalization is narrowed down further. We hereby think of small-scale initiatives but also refer to the definition of deinstitutionalization as being recently described by the *European Expert Group on the Transition from Institutional to Community-based Care* (20191). In this description it is stated that deinstitutionalization is not only realized by focusing on ‘location’ but ‘autonomy’ and ‘style of service’ are equally important when doing so.

In our recent research project (see Remmery et al., 2022), we address a problematic dichotomy which has increasingly been produced by disability policy and practice during the last decades, based on the predominant idea that the location is the foremost important element in the lives of people, and thus disabled citizens living in residential institutions is something ‘bad’ to avoid and disabled citizens living in the community is ‘good’ and desirable (EGTICC, 2021).

1 https://deinstitutionalisation.com

There is increasing research evidence on the problematic situations of disabled people who are ‘living in the community’, and lack high quality professional care and support. This phenomenon is named in international literature as ‘institutionalisation@home’ (Beadle-Brown et al., 2007; CECHR, 2012; Vervliet et al., 2019), ‘trans-institutionalisation’ (Högström, 2018; Knibbe & Horstman, 2019), ‘community institutions’ or ‘institution-like practices within community care’ (Tøssebro et al., 2012), ‘asylum without walls’ within the community (Hall, 2005), or ‘exstitutions’ (Milligan & Wiles, 2010). These developments refer to the often un-intentional reproduction of institutional, professional cultures with controlling or oppressive logics and perceptions of care and support regardless of the living environment, the lack of social resources (such as facilities), or the lack of tolerance for difference in social interactions in society (Bantry-White, 2021; Hall, 2005; Högström, 2018; Knibbe & Horstman, 2019).

In Para 16 we see reference to the elements of autonomy and style of service, resp. in “decision making” and “(compulsory) treatment”, but throughout the draft the focus is all too limited on location. We therefore think it is important, not to say fundamental, that when describing and promoting deinstitutionalization we cannot only focus on the aspect of ‘location’ but also put ‘autonomy’ and ‘style of service’ as a triptych in the discussion. In this respect, we ask ourselves if the “development of a range of individualized supports and inclusive mainstream services in the community” doesn’t imply a broader definition than the one used in de draft, referring to the development of new, person-centered, support services and initiatives.

1. Key elements used

It is obvious that the proposed Convention uses independency and autonomy (cfr. *ableism*) as a primordial principle (as, e.g., mentioned in Para 7), hereby referring to the classic-vigorous translation based on 'active citizenship' and the expectations such as participation, decision-making and speaking out. On the other hand, the text refers, a.o., to persons with high support requirements in an effort to include these citizens in this framework of independency. One can observe the discrepancy and a *contradictio in terminis* in this statement: especially people with high support needs do not always comply with these expectations.

The question can thus be stated if, by doing so, we impose values, norms and expectations without respecting every person’s individuality and (inter-) dependency. This is not an issue of underestimation (if transferred to all people with disabilities this does apply) but even more embracing reality and diversity in itself. We see this in the plea for an “independent life in the community” (Para 15), the plea for “equal access to employment, prohibiting sheltered or segregated employment” (Para 102) or find a telling example in Para 99 where by ensuring “that persons leaving institutions have access to transportation, are free to move about in the city, rural areas or their neighborhoods” the assumption seems to be that every person can do this independently. Another example of this issue can be seen when the full respect for the person’s “self-knowledge, will and preferences” is described, assuming that the conditions for achieving this on an independent base are available for every person with a disability. So, our plea is to embrace the diversity of support needs, … rather than formulating the principles of independency and autonomy to such an extent that almost no citizen, with or without a disability, can meet it during a lifetime.

When recognizing diversity, we state that realizing deinstitutionalization can be better achieved by embracing the aforementioned triptych of concepts but also by validating, in all aspects, universal human interdependency (see Roets et al, 2020). Rather than postulating independency (as an opposite to dependency) we should embrace interdependency; more or less intensive, temporary or lifelong but always universal to human nature. When doing so, the principles as mentioned in Para 64 (“They should provide services solely under the direction of persons with disabilities, or their family members in respect of children with disabilities”), Para 22 (“Support should be individualized, personalized, and offered through a variety of options”), Para 92 (“a human-rights and person-centered model”) and Para 70 (“no support person should be appointed against the will of persons with disabilities”) should be embraced in every possible setting and/or environment in order to realize deinstitutionalization to it’s full extent. We believe that by widening the understanding of deinstitutionalization (from a focus solely on location) and doing justice to the wide variety in support needs, the aims of the Convention are more likely to be effectively realized.

A second ambiguity is seen in the plea for “autonomy, choice and control” (in, e.g., Para 17) while, on the other hand, certain choices are actually prohibited or “can never be considered as a choice” (see Para 8). In our opinion, embracing the variety in support needs and, thus, support services and initiatives also implies that personal choices can be validated even when they don’t accord to the proposed framework completely. From this stance, we see a risk emerging that the critique, rightly so, that freedom of choice was (completely) restricted in the past when residential care was the only option when in need of care and support, can also be expressed when a (free) choice for residential care is forbidden or restricted in any case. Of course, when “leaving institutions” is the wish and desire of a person with disabilities it is obvious this choice needs to be honored immediately and unconditionally. The question we want to raise is what position we want to take when someone chooses (informed, free and, thus, referring to complete choice and control over the kind of support) for, e.g., shared services or, as mentioned in Para 31, “housing with medical or support packages”. It seems, from our point of view, nothing less than obvious and necessary that “the person’s self-knowledge, will and preferences” (cfr. Para 74) are fully respected in every aspect and, thus, by every service provider one chooses. Therefore, we state that the needs described under Para 74 apply to everyone needing support and help in whatever setting the services are organized.

In Para 88 we read the plea for “access to a variety of accessible, affordable and quality mainstream services”. We would like to underline the relevance but also challenge of this aspect by highlighting the importance of professional expertise and knowhow too. In Para 63, when stressing “alternatives to verbal communication” or in Para 83, when referring to “appropriate adaptations”, we notice this issue: realizing supported communication or individualized adaptations and technological support (a.o. for people with high support requirements) implies professional expertise to realize this to its full extent. Making these services accessible, by unlocking specialist knowledge, seems to be an important surplus in realizing inclusion and interdependency, not least when applied to guaranteeing children to realize their full potential.

Lastly, we would like to place a critical stance regarding the proportionality that inspires current policy and, to a certain amount, this draft. Much emphasis is placed on the support from family, the personal network such as friends and the community. Moreover, we would like to stress the evidence (see Remmery et al., 2022) that, in particular for people with high support requirements, we can frequently observe an interaction between several risks contributing to a significant vulnerability and (inter-) dependency and, thus, specific challenges when realizing deinstitutionalization. We hereby highlight the already mentioned persons with high support needs, resulting in a need for lifelong and specialist care (also referring to people with multiple or acquired disabilities), people who cannot 'claim' their own rights nor have the abilities to manage their individual funding (as described in Para 84 and Para 86), people for whom verbality is not a means (sometimes resulting in ‘difficult behaviour’ as a way to communicate) or for whom self-reliance (in the classic-vigorous translation based on 'active citizenship') is a theoretical construct, people who cannot rely on a strong or empowered personal network, or people affected by growing poverty and social inequality.

We would thus like to stress the importance of a nuanced view where the (responsibilities of the) welfare state are still confirmed and where this appeal is not conducted in a way where responsibilities in support and care are solely pushed away to family, friends, the neighborhood, and mainstream services (also referring to the issue concerning specialized care as mentioned earlier). Only by cooperating and placing the person with a disability – with her of his own values, expectations, desires and limitations – at the center we believe deinstitutionalization can be realized to its full extent.

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