

Tina Minkowitz, Esq.

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**Comments on draft General Comment No. 5 on Article 19**

The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) is a DPO and human rights organization that aims to provide strategic leadership in human rights advocacy, implementation and monitoring relevant to people experiencing or labeled with madness, mental health problems or trauma. In particular, CHRUSP works for full legal capacity for all, an end to forced drugging, forced electroshock and psychiatric incarceration, and for support that respects individual integrity and free will.  CHRUSP has been granted Special Consultative Status with ECOSOC and has engaged actively with the CRPD Committee and other mechanisms in the field of human rights and disability. See [www.chrusp.org](http://www.chrusp.org).

Tina Minkowitz is a lawyer and survivor of psychiatry who contributed to the drafting and negotiation of CRPD on behalf of the World Network of Users and Survivors of Psychiatry. She is President and Founder of CHRUSP. Contact at [info@chrusp.org](mailto:info@chrusp.org).

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Comments proceed in order of the draft text.

1. Para 3, children’s evolving capacities are not limited to preservation of identity, please insert ‘and their right to’ before ‘preserve.’
2. Para 6, please substitute ‘integral to’ rather than ‘a precondition for’ implementation. Precondition suggests that social and economic components may excuse postponement of civil rights such as legal capacity and liberty.
3. Para 9, suggest referencing UDHR Article 22 regarding realization of economic/social/cultural rights necessary for free development of personality.
4. Paras 10 and 11, appears odd to refer to legal capacity and to deinstitutionalization in other treaties without bringing up CRPD Articles 12 and 14, but perhaps unavoidable given structure. Also CRC Article 12/CRPD Article 7.3 deal with children’s right to participate in decision-making comparable to legal capacity.
5. Para 14, please insert a reference to exclusion of people with psychosocial disabilities from independent living frameworks and segregation under mental health services, suggest after subpara (f), as follows:

‘Failure to adequately conceptualize the right to personal assistance and individualized support for persons with psychosocial disabilities, who instead continue to be segregated when their right to live in the community is equated with the development of community-based mental health services;’

1. Para 15 – in general, very well done but it is not clear how these definitions relate to the normative content as specified further below. It would help to make these linkages, e.g. by specifying that these core concepts frame the normative values underlying the structural changes in society and in services that are to be put into practice to realize the rights protected in Article 19. Deinstitutionalization requires the implementation of strategies shaped by the values of independent living, community living, life settings outside of institutions, and personal assistance, as defined in paragraph 15. (See also comments on para 42 below, which link to these points.)
2. Para 15(a), excellent definition of independent living.
3. Para 15(c), suggest to insert ‘as institutions’ before ‘large or smaller group homes.’ While clear from remainder of paragraph, the sentence out of context could be misunderstood.
4. Para 15(d), delete ‘an individual needs assessment and’ and insert after ‘life circumstances,’ ‘and is open to what she or he might design to meet his or her particular needs.’ The difference is between user-designed support and a gatekeeper who passes judgment on needs, making errors and having authority to deny a wanted service and limit the offer to an unwanted one. Also insert ‘design the service and’ before ‘decide by whom,’ and add at the end of that sentence, ‘and to instruct and direct service providers.’ Services may be newly imagined and created to meet newly articulated needs, hence design and instruction are needed. In the following sentence, delete ‘requirements, capabilities’ before ‘life circumstances’ as those terms suggest third-party oversight over the degree of control a person may have. While there are practical limitations in anyone’s control over any kind of service, as it is an interaction between human beings, best to leave it open irrespective of any person’s perceived capabilities or needs at a particular moment in time.[[1]](#footnote-1) In the next-to-last sentence, insert at the end ‘, with others having the obligation to inquire about and respect his or her will and preferences.’
5. Insert after paragraph 20, new paragraph as follows:

‘Furthermore, all components of Article 19 are equally applicable to persons with all types of impairments, and states cannot restrict eligibility based on impairment. The Committee has observed that some states parties deny eligibility for personal assistance services to persons with psychosocial disabilities,[[2]](#footnote-2) and offer them only programs and services directed by mental health professionals. This contravenes Article 19, which guarantees to all persons with disabilities the same right to independence and autonomy in the design of services to meet their needs, and the same right to access the entire spectrum of services defined according to area of need (e.g. housekeeping, transport assistance) and not according to their impairment.’

1. Para 21: While it is legitimate for young persons with disabilities to want to be with people of their own age and culture, please rephrase and reframe so as not to suggest that institutional cultures are in anyway natural for older people, recalling that young and old alike have a right not to be institutionalized and to receive and create services and housing options (including co-housing models) that are acceptable to them. Cultural difference is not limited to age; it is ethnicity, sex, political beliefs, sexual orientation, religion, and more. Some of these are addressed in para 24 but only as non-discrimination in the wider community; differences requiring mutual adjustment within disability community itself and service and support cultures need to be addressed along these dimensions also. Concept of acceptability may help here and elsewhere to be further developed.
2. Para 22, delete ‘including the young’ and insert ‘, of any age,’ after ‘persons with disabilities.’
3. Para 25, substitute ‘choice’ instead of ‘legal capacity’ after ‘Furthermore, they might not be allowed to exercise.’
4. Para 26, substitute ‘always take place within a context of social interactions and mutual obligations’ instead of ‘are always bound to social interactions’ as original was not clear in meaning.
5. Insert after paragraph 26, new paragraph:

‘The right to not be obligated to live in a particular living arrangement furthermore depends on the right to be free from impairment-based detention under Article 14.[[3]](#footnote-3) Persons who wish to leave an institution must not be prevented from doing so, and must furthermore be provided with information about housing and supports, and with financial assistance and/or other forms of social protection as transitional support.’

Comment: It is important to address the immediate obligations contained in 19(a) linked with both Articles 12 and 14. You may wish to elaborate on this further; Articles 5 and 28 are linked as well. Institutionalization is not considered a legitimate way to meet needs for social protection for the general population, nor is it legitimate to hold an individual in prison longer than the sentence even if the person has no home. The same principle must be applied to allow people with disabilities at will to leave institutions, and to be provided with necessary social protection that does not restrict their freedom and that is not required to be provided through disability-specific programs.

1. Paras 27-31, I am missing a coherent philosophical approach to services under 19(b) that would ensure we are talking within a social model of disability, a human rights and non-discrimination model, one that centers the person concerned as the chooser and creator of needed supports together with chosen supporters. The approach taken under Article 12.3 relates closely with disability-rights activism for personal assistance not only as one type of individualized support service but also as a philosophy or system of values in which support has as its purpose and obligation the respect for the individual’s autonomy, will and preferences. Here we are in the realm of a person’s effective access to activities and inclusion in community, outward action and relationships beyond the exercise of decision-making per se. It should be an extension of those same values, respect for and amplification of a person’s autonomy by creating the supports necessary for any person to participate in community and in desired activities. I would argue that personal assistance as value and philosophy should be at the center of how we understand services under 19(b), and that when generalized services are offered as well to meet the needs related to living in community and preventing isolation, they should demonstrate an adherence to the values of personal autonomy and control, with respect for the knowledge of the person concerned about his/her own needs and the best ways to meet them. This is in my opinion what differentiates Article 19 services from Articles 25 and 26.
2. Para 28, change ‘might be necessary for’ to ‘should be offered to’ before ‘persons who have lived in institutional settings for a long time’ and add at the end of that sentence, ‘ensuring respect for the person’s will and preferences and the option to move directly into integrated housing. This ensures that deinstitutionalization and transitional housing remains subject to the individual’s will and preferences. Also insert, ‘Another kind of residential service offers temporary support as a respite from the person’s usual living arrangement, as an option offered to people in situations of crisis.’ This brings peer-run crisis respites by and for people with psychosocial disabilities within the framework of Article 19. It is different from ‘respite’ offered to caregivers, as crisis respites meet a person’s own need for temporary support. I would in addition elaborate further on personal assistance here and not only rely on the definition in para 15.
3. Para 29, substitute ‘animals’ for ‘dogs’ after ‘guide dogs/ service’. Also I question the inclusion of social work services as a personalized service. Social work is a very general professional designation that can operate in a highly interventionist manner, and cannot be considered an individualized service except in the same sense that health care and rehabilitation are individualized; in my view social work belongs more properly under Article 26. If something more like ‘advocacy and assistance in claiming rights and benefits’ is meant, it would be helpful to specify this as a descriptive need and task, rather as ‘dressing aids’ is done. In addition it would be helpful to use more descriptive language overall for the needs and tasks with which assistance might be provided.
4. Para 30, add after ‘segregation from the community”’ the following: ‘and must in actuality be suitable to this purpose.’ Also it is not clear what is meant by ‘community support services’ and whether this means the same as ‘general’ rather than ‘individualized’ services in para 31. It is problematic since nowhere is it explained how non-individualized services relate to 19(b) given the characterization of 19(b) services as individualized in para 27’s introduction to this section. Furthermore, the services named here are not centered in the autonomy of persons with disabilities, and it is not clear for instance whether ‘parent’s night out’ refers to parents with disabilities, parents of children with disabilities, or parents of adults with disabilities (in which case some other model is needed, so as not to infantilize adults with disabilities). The caveat at the end of the paragraph does nothing to reassure me on this question. It would be helpful to give examples of good examples, perhaps like some of the peer-run services by people with psychosocial disabilities, where support groups exist that aren’t individualized but respect people’s autonomy and choices; also community-run non-professional support groups developed with and for people with intellectual disabilities.
5. Para 31, please see comment on para 30 re ‘general’ services, consider substituting simply ‘all’ instead of ‘both individualized and general’, and please add at end of sentence, ‘and living independently.’
6. Para 34, impairment and age are cross-cutting in relation to each other; but the framing makes it invisible that e.g. deafblind children would be in both the categories given as examples. Also please add ‘of the range of accessibility needs’ after ‘analysis’ in the last sentence.
7. Para 38, it’s not clear what is meant by referring to services as ‘individualised’ or how ‘personal assistance’ could be offered in a package with housing, given the strong emphasis on user control in the definition (para 15). In addition this para does not adequately capture the situation facing people with psychosocial disabilities. Please add after ‘cost efficiency,’ ‘or, particularly with respect to people with psychosocial disabilities, as a way to secure individuals’ compliance with undesired services.’ Following this, reorder the next two sentences and add at the end of the sentence beginning ‘the possibility to choose,’ ‘and cannot be undermined by design or accident.’ Substitute ‘Furthermore, the premise of cost efficiency’ for ‘However, this premise’ before ‘can be rebutted economically.’
8. In para 40(a), insert after ‘live,’ ‘and whether and where to access services.’ Also, insert here or in separate subparagraph, ‘Regulatory frameworks that authorize deprivation of liberty based on actual or perceived impairment are incompatible with the right of persons with disabilities to live independently and be included in the community on an equal basis with others.’
9. In para 40(b), insert ‘affordable and’ before ‘accessible,’ and add at the end of the sentence, ‘that is not tied to receipt of services.’
10. In para 40(d), substitute ‘human rights-compliant’ instead of ‘human rights-based’ which has been used in misleading ways to promote service models that in fact violate CRPD such as coercion-authorizing mental health laws. If the term ‘human rights-based’ cannot be omitted, be sure to specify that it is meant to exclude such violative practices. In addition, please insert at end of sentence, ‘defined according to needs in any area of life and not based on impairment.’
11. Para 41, please insert after ‘immediately applicable’ ‘and enforceable’.
12. In para 42, the reference to margin of appreciation on ‘mode of services’ is confusing, especially given the weaknesses of the normative section on 19(b) as commented above. Consider referring back to the definitions and (as suggested) overarching framework in paragraph 15 for the distinction between institutionalization and community-based services, e.g. by adding after ‘article 3 of the Convention,’ ‘according to the values and concepts outlined in paragraph 15 of this General Comment.’ Consider also changing ‘the mode of services’ to ‘programmatic implementation.’
13. Para 43, it should be taken into account that the minimum core elements contain civil rights that are immediately applicable irrespective of any minimum core analysis. Perhaps it might be stated that the 19(a) obligations are immediately applicable on both grounds.
14. Para 45, it is confusing and incorrect to elaborate on immediate obligations related to the civil right under 19(a) as part of non-discrimination as an exception to progressive realization of 19(b) and 19(c). These should be separated analytically as well as programmatically. It is necessary regarding 19(a) to specify repeal of laws that authorize involuntary institutionalization, deprivation of legal capacity, deprivation of liberty based on actual or perceived impairment as elaborated in the Guidelines on Article 14. These forms of deliberate exclusion and discriminatory detention need to be addressed explicitly as a violation of article 19 as well as article 14, and not merely gestured towards as ‘laws, policies and practices that prevent persons with disabilities from choosing their residence.’
15. Furthermore, still on para 45, the immediate obligation means that individuals need to be promptly released from confinement against their will in disability-specific settings such as mental health facilities; all necessary measures should be taken to ensure that both public and private facilities that confine persons with disabilities against their will are directed to cease preventing individuals from leaving who so choose, and that such individuals are given immediate and priority access to social protection programs to secure their basic needs. This is an immediate obligation in consequence of the duty to end the practice of arbitrary detention. It cannot be met merely by the existence of review mechanisms, as such mechanisms have traditionally operated as case-by-case legitimation of detention and the retraining to respect CRPD norms would have uncertain results; furthermore review mechanisms by nature operate slowly and presume resistance by authorities seeking to continue confinement. Review mechanisms can play a progressive role if their mandate allows them to issue injunctions requiring the release of all persons so confined, but when discussing the obligations of states parties as such, all branches and powers of government must be utilized for the quickest result possible. Whichever agency is in the best position to direct the immediate release of all individuals confined in disability-specific regimes of deprivation of liberty such as mental health involuntary commitment and involuntary treatment, must be authorized to do so by the state party concerned, in order to comply with their immediate obligations under Articles 12, 14 and 15.
16. Still further on para 45, note that release does not require any person to leave if she or he wishes to remain in the place where previously confined, it is a right to have the detention cease and is not the same as the process of deinstitutionalization that may take more time to support the individual to discover and articulate how they choose to live.
17. Para 47, change ‘correspond with a states’ party duty’ to ‘impose on states parties a duty’.
18. Para 48, again the immediate obligations to end disability-based detention need to be highlighted. Please add ‘or receive services’ before ‘in institutions’ and then ‘or allow them to be removed from the community for periods of time and confined against their will based on an actual or perceived impairment.’ These laws and practices place people with psychosocial disabilities in a situation of extreme vulnerability and disadvantage and violate their Article 19 right to live independently and in the community both for the period of confinement and as a perpetual threat, that imposes on them a pariah status and constitutes an obstacle to their participation and inclusion.
19. In para 48 or 49, or as separate paragraph, please add that the obligation to respect also entails the obligation to release all individuals who are being confined against their will in mental health services or other disability-specific forms of deprivation of liberty that are under the control of public officials. Furthermore the obligation to respect requires that that public authorities such as courts do not uphold or acquiesce in such detention regimes.
20. In the section on Obligation to Protect (paras 50-53) it would be appropriate to mention the duty to ensure that private individuals and entities do not confine persons with disabilities or prevent them from leaving any particular facility or living arrangement. This would apply to both confinement by family members and confinement in medical and social service institutions, and in religious settings that practice disability-specific detention (e.g. prayer camps). Monitoring mechanisms are not sufficient, nor is ‘being hidden’ or ‘isolation’ the sole problem, rather the mere fact of confinement against one’s will violates the Article 19 right to live independently and in the community as well as Articles 12 and 14. States parties must ensure that once a private entity or individual is found to be confining a person with disability there is an immediate remedy allowing the person to be released and have priority access to social protection programs. See also comment on para 45 that on release as distinct from deinstitutionalization; release from detention is a right to choose whether or not to remain in a particular facility or home or other place, and to not be prevented from leaving.
21. In para 51, substitute ‘individual’s will and preferences’ instead of ‘individual requirements.’ If necessary to make adjustments with respect to children with disabilities, indicate that this is to be according to the evolving capacities of the child, in line with Article 3 principles and 7.3. Do not use language that degrades the rights of adults with disabilities in order to encompass the rights of both children and adults. After ‘interest of the service provider,’ add ‘or the service provider’s view of the “best interests” of the person concerned.’
22. In para 52, add after ‘certain services,’ ‘either through restrictive eligibility criteria or narrow definition of the service that fails to account for all groups’ needs on an equal basis.’ Consider also substituting ‘the opportunity to receive person-directed/user-led services’ for ‘the provision of certain services’ to indicate that it is the overall framing of independent living services that is at issue; e.g. people who are not Deaf will not need sign language interpreters and ‘certain services’ might lead to absurd implications.
23. Para 54, add ‘or unaffordable’ after ‘inaccessible’ (housing). Also add ‘or services that are unacceptable’ after ‘limited access to disability support services.’
24. Para 55, it is crucial to ensure that emphasis is placed on involvement of marginalized sectors that are often left out because they organize separately from the disability community, because they are displaced by service providers or family members, or for other reasons. People with psychosocial disabilities, people with cognitive disabilities such as dementia and Deaf people may be mentioned, as well as women with disabilities and indigenous and cultural minority persons with disabilities.
25. Para 56, it is preferable to refer back to ‘individualized support services and inclusive community services’ or ‘these services’ rather than introduce ‘community support services’ which could be interpreted according to states parties’ own definitions. Following sentence, ‘such services’ should replace ‘support services’. In addition, the process of deinstitutionalization itself requires programmatic measures to attend to the needs of all institutionalized individuals to discover and articulate their will and preferences about living arrangement, support services and participation in community. This will be relevant to their choices at the outset of leaving an institution, and should not be merely displaced to the future by providing for residential services as a transitional option as indicated in paragraph 28 of the draft GC. Programmatic measures should be noted and provided for as budgetary outlays, along with evaluative components to ensure that they are working and continued as long as needed until all institutional settings, using the criteria in paragraph 15(c), are closed.
26. Para 57, consider adding as example of reducing autonomy, ‘such as a requirement to be under medical supervision or comply with prescribed treatment.’
27. Para 58, good, and still the transversal references to non-exclusion are also needed as suggested in my comments. Also please separate persons with psychosocial disabilities from persons with intellectual disabilities and do not use the term psychosocial impairment.
28. Para 59, I am concerned that the support needs of people with psychosocial disabilities are not well understood as arising from barriers within society, and thus will be poorly addressed under the framework indicated here. Furthermore, the obligation to ‘take into account’ will and preferences, and have persons ‘participate’ in decision-making can allow substitute decision-making contrary to Article 12. Suggest instead of the assessment described here, an interactive process based on descriptive needs and available mechanisms to provide or design supports, in accordance with the will and preferences of the person concerned. Eligibility should be based on an expressed need rather than an external assessment of barriers, which will be prejudicial to persons with psychosocial disabilities when they and/or assessors are not accustomed to viewing their needs in terms of social barriers. This will result in unfair exclusion from Article 19 services and relegation to Article 25 medical model services within a health framework. States should if necessary design tools to prioritize the allocation of services to those with the greatest need, while guarding against discrimination based on the nature of different needs or type of impairment.
29. Paras 60-61, good but similar concern about ‘disabilities that hinder participation in society’ as parameter for conditionality of cash transfers, particularly as it fails to address poverty and may be insufficiently responsive to needs of people with psychosocial disabilities for reasons mentioned above regarding para 59.
30. Para 62, please clarify what is meant, and what is the remedy, regarding personal budgets not giving individuals access and control over community support services.
31. Para 64, the reference to professional training being essential to ensure respect for will and preferences is unsupported, it is contrary to Article 12 and must be deleted. This is absolutely not the case with respect to mental health training to support people with psychosocial disabilities, who as a group are disproportionately denied access to self-designed supports and free choice of supporters. While persons with disabilities may choose to access professionally-operated services for any number of reasons, this cannot be for the reason given and for that reason the sentence should be deleted. Change ‘professionals’ in the first sentence to ‘personnel working in disability-related services’ and rephrase last sentence as ‘Personnel who worked or currently work in residential institutions should be retrained and assessed to determined their fitness and readiness to actively contribute to deinstitutionalization and the transformation of support services.’ The changes necessary with respect to mental health service providers are much greater than most other disability support workers, as they have to unlearn legalized violence and coercion and substitute decision-making in addition to paternalistic and objectifying service cultures.
32. Para 65, ‘programs for independent community living’ rather than current phrasing which suggests not all community living is independent, and ‘institutionalized’ rather than ‘institutional’ care.
33. Para 66 is good and does not replace the need for measures suggested above under ‘respect’ and ‘protect’ to secure immediate release from disability-based detention.
34. Para 69, change ‘a diverse range’ to ‘the full range’ of persons with disabilities and instead of grouping women and children, specify, ‘including organizations of women with disabilities, older persons with disabilities, children with disabilities, persons with psychosocial disabilities, and persons with intellectual disabilities.’
35. Para 70, again ‘human rights-based approach’ is too vague as we have seen mental health laws allowing involuntary measures so characterized. Substitute ‘human rights-compliant’. Consider ‘persons with disabilities in particular circumstances’ as better than ‘particular groups’ to describe the examples given. It would be helpful to mention responsiveness to older persons with disabilities, despite the absence of a specific article, as a significant and growing constituency.
36. Para 72, include in first sentence, ‘require them to suppress their own needs and instead serve those of others.’
37. Para 75, suggest ‘service providers’ rather than ‘professionals’ and ‘actual lives’ rather than ‘positive image’.
38. Para 78, replace ‘ensures’ with ‘guarantees’ in first sentence. Furthermore, there should be an indication that action is required to implement the right to legal capacity which is a necessary precondition for equal enjoyment of Article 19 rights, including law reform and remedies to enforce the rights against public and private actors who seek to deny individuals control over their living arrangements and support services.
39. Para 79, add, ‘Enactment and enforcement of a legal prohibition of impairment-detention is a necessary precondition for the full and equal enjoyment by all persons with disabilities of the right to live independently and be included in the community.’ (In addition, transversal references to immediate obligations and remedies related to the overlapping civil right of 14 and 19(a) as indicated in comments above.)
40. Para 84, add, ‘Respecting the rights of parents with disabilities and providing support for them to carry out parenting tasks is also necessary for the right to independent living and community participation.’
41. Para 86, add, ‘Provision of professional mental health services may fall under Article 25 or 26, and overlaps with the need for individualized supports and access to inclusive community services under Article 19. Mental health services need to be transformed to comply with human rights norms, but even transformed services do not in themselves satisfy Article 19; persons with psychosocial disabilities have the right to design forms of support that align with their own understanding of their life journeys and needs outside any professional narrative.’
42. Para 92, add ‘independent living and’ before ‘community support.’
43. Para 93, add ‘or places of confinement or institutional models of care’ after ‘new residential institutions.’
44. Para 94(a), separate the two sentences. Add at the end of the first sentence, ‘including provisions in mental health laws that authorize confinement against the person’s will. Ensure that all individuals are allowed to leave any such facility in which they have been confined, or to remain according to their own will preferences.’ This is essential to equal and full implementation of the immediately applicable civil right to be released from arbitrary detention, contained in both 19(a) and Article 14.
45. In connection with the second sentence of 94(a), add, ‘Ensure that social protection programs are designed to meet the needs of the diverse range of persons with disabilities on an equal basis with others.’
46. Para 94(d), separate ‘persons with psychosocial disabilities, persons with intellectual disabilities’. Note that this obligation is separate from the independent obligation to ensure that any person who wishes to leave is not prevented from doing so, and is eligible for social protection programs.
47. Para 94(g), add ‘affordable and’ before ‘accessible’ and ‘affordability,’ before ‘accessibility,’ before ‘and responsiveness.’ Add, ‘Such housing must be integrated into the general community and made available to persons with disabilities including those who do not choose to access support services.’
48. Para 94(i), add after ‘support services’ ‘for all persons with disabilities.’

1. Argument here similar to Committee’s in GC1 paras 13-15; caution on concept of mental capacity as well as its conflation with legal capacity. [↑](#footnote-ref-1)
2. See Concluding Observations on Austria. A colleague in Argentina has highlighted even more dramatically the denial of personal assistance while offering only mental health therapeutic accompaniment. She finally won and was able to choose her own supporters and the nature of the support. [↑](#footnote-ref-2)
3. Guidelines on Article 14 (2015) paragraph 9. [↑](#footnote-ref-3)