María Soledad Cisternas Reyes. Independent expert. Former member of the CRPD Committee.

**Draft GC Article 19**

I’d like to commend the CRPD Committee for the draft GC on Art. 19. The document is categorical in the esential aspects of the right to living independently and being included in the community, making it clear that institutionalization is a “figure” in contradiction with Art. 19.

Paragraph 47 tries to combine or make a balance between the person with disabilities` “right to choose”, and on the other hand, that it is not the state’s obligation to maintain institutions, as part of Art. 19. The concepts are in line with CRPD.

I’m concerned about the situation in many developing countries, in which there are persons with disabilities who are homeless and who live in the streets, lacking food and in ocassions dying from starvation or the cold and winter rain.

As the introduction of the 2030 Agenda reads, it’s necessary to be free from fear and need. In fear, lack and poverty it’s very difficult to choose, perhaps impossible.

In order for “no one to be left behind”, the situation of persons with disabilities in these precarious conditions may be protected under Art. 28 under social protection.

We can not forget that the “freedom to choose” requires a consistent effort of the states to create the conditions that facilitate the exercise of this freedom. For this reason the factors of poverty and discrimination require to be adequately addressed through public policies to enable the actual implementation of Art. 19. This is a systemic change.

Please see my opinions on some paragraphs:

(Par. 7) Article 19 entails civil and political as well as social, economic and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to independent living and being included in the community can only be realized if all civil, social and cultural rights enshrined in this norm are fulfilled. Comment: Civil, political, social, economic and cultural rights can be agreed on, since Article 19 covers a wide range of rights and infers the exercise of other interdependent rights, as reflected in Chapter 4. Modern human rights theory recognizes that in order to be realized, all human rights require resources*.* Comment*:* I think this mention of the "modern theory of human rights" is not well founded. It is a very generic reference. It is dangerous to say that all human rights require resources since this can be an excuse for states to not fulfill them (relate this budgetary aspect to letter C and J of paragraph 14 of this text). In addition, we can not ignore the fact that in particular the exercise of civil rights, subject to the principle of immediate compliance, may not require resources, for example the right to liberty and security of the person, or the right to privacy. The need for resources can be expressed elsewhere in the GC commentary, as in the final chapter on "national implementation".Systematic realization also requires structural changes which have to be taken step by step, no matter whether civil and political or social, economic and cultural rights are at stake.

(Par. 14 f)

Negative attitudes, stigma and stereotypes that prevent persons with disabilities \* Comment: I suggest to add “…, particularly women and girls with disabilities,…” from being included in the community and accessing available support;

At the end, it might be added:

* Lack or insufficiency of a real implementation of an inclusive education system. (Article 24)
* Lack or insufficiency of specific actions to raise awareness of society regarding the right of persons with disabilities to living independently and to be included in the community (Article 8)

(Par. 15 b - d)

(b) **Community living:** The right to be included in the community … These can be elections as well as public meetings of local governments, sports events as well as theatre festivals \*. Comment; It might be added “…and any other activity in which the person with disability wishes to participate.” Although community may primarily be understood…

(d) **Personal assistance** refers to person-directed/user-led human support … It is based on an individual needs assessment and a person/user’s life circumstances. Comment: According to the last jurisprudence of the Committee I suggest to say requirements instead of needs. The service is led …

 (Par. 21) Different cultures can also challenge the concept of …, hence not allowing young persons with disabilities to develop an identity and live their life in an age-appropriate mode -as ‘young’. Comment: a phrase might be included underlying the same idea in relation to elderly persons with disabilities, who are subjected to schemes and rhythms of life different to what they want.

(Par. 29) Individualised services encompass a whole range … They are not restricted to services inside the home, but must also be able to extend to the spheres of employment, education or political and cultural participation. Comment: Please, consider that the support services can also give support to the execution of various procedures, even for the execution of contracts.

(Par. 30) The text does not specify other services… They may be named respite services, Comment: It is not appropriate to continue with the expression "respite services", since they carry a negative and stigmatizing burden in relation to the interaction of personal care towards a person with disability. supported parenting or parent’s night out services in one country…

 (Par. 33)Accessibility of community facilities, goods and services, as well as inclusive education and health Comment: I suggest to add “…the exercise of the right to inclusive education and the right to health…” are a sine-qua-non for inclusion and participation of persons with disabilities in the community.

(Par. 34) … Therefore, effective data collection disaggregated by age, sex, ethnic background, social condition, refugee, asylum-seeking, migrant situation \* Comment: I suggest to add “…urban and rural life…” and analysis are of paramount importance.

(Par. 39) …to allow for spontaneous participation by people with disabilities within the community. Comment: according to the CRPD, “persons with disabilities”.

(Par. 42) In order to achieve the realization of social and cultural rights, States parties must take steps to the maximum of their available resources (art. 2 (1) ICESC \*) Comment: Add “…and art.4 (2) CRPD)”.

Comment 2: I suggest clarifying for readers the final part of the paragraph in relation to "but not to the question of replacement". This idea is very important for the expression of the will and preferences.

47. The right to decide where, how and with whom to reside also embraces the 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, the right to choose a residential, institutional setting does not correspond with a states’ party duty to maintain institutions or to ensure the availability of residential support services.

(Par. 51) … in institutions, protect children from being abandoned or institutionalized on the grounds of disability and establish appropriate mechanisms to detect \* Comment: to add “…report and sanction…” situations of violence \* Comment: to add “…and abuse…” against persons with disabilities by third parties.

(Par. 56) States parties should Comment: I suggest to replace by “must” adopt a strategy for de-institutionalization…

(Par. 59) States parties should ensure that eligibility criteria for access to support incorporates the following elements: Comment: “should ensure” is juridically very weak. I propose “The States Parties shall incorporate the following elements into the eligibility criteria for access to assistance” The assessment should be based on a human rights...

(Par. 60) Cash transfers …. States parties should not Comment: I suggest to replace by “must not” add to the hardship faced by persons with disabilities, by reducing their income in this period of austerity measures.

(Par. 64) States should Comment: I suggest to replace by “must” ensure that professionals are adequately trained on independent and community living. In certain contexts, Comment: I suggest to delete “In certain contexts”, as guidelines of paragraph 64 apply to all contexts professional training is essential …

(Parr 66) States parties should also ensure that international cooperation… After situations of disaster, it is important not to rebuild barriers. Comment: I suggest to add “art. 11”. This idea is repeated in Par. 77)

(Par. 72) Cultural norms and values … address gender-based inequalities in accessing support and social protection. Comment: To add the reference to GC Nº 3 on Women with Disabilities

(Par. 74) When it comes to social interactions... States parties should Comment: I suggest to replace by “must” provide devices, such as adapted wheelchairs for practicing sports as well as personal assistance that can facilitate the inclusion of adolescents with disabilities in their peer networks.

(Par. 76) … the inclusion of standards of universal design in a variety of sectors, and the establishment of accessibility standards for housing. Comment: To make reference to GC Nº 2 on Accesibility and to Habitat III Urban Agenda.

(Par. 77) … It is also important that barriers are not rebuilt after natural disasters or armed conflicts. Comment: I suggest to add “Reconstruction processes must ensure full accessibility for the independent and community life of persons with disabilities”.

(Par. 85) Independent and community living are inherently linked to inclusive education (art. 24), health care (art. 25), rehabilitation (art. 26) and work and employment (art. 27).

Comment: I suggest to delete the phrase refering to art 25, 26 and 27 to continue with specific paragraphs for each right. For example, the right to inclusive education should have a paragraph with its own numeration: paragraph 85

(Par. 85) The Right to Inclusive education (art. 24) requires recognition of the right of persons with disabilities to live independently and enjoy inclusion and participation in the community…

Comment: Make reference to GC 4 on the Right to Inclusive Education.

(Par. 86) General health facilities and services (art. 25) should Comment: I suggest to replace by “must” be accessible …

(Par. 87) There is interdependence... At the same time, the purpose of rehabilitation is to enable persons with disabilities to participate in the community. Comment: I suggest to add “The rehabilitation of a person with disability must always respect his/her free and informed consent”. Rehabilitation is dominantly relevant in relation to education, employment, health and social matters.

(Par. 89) … Disability-related costs should be covered by additional resource allocations to avoid persons with disabilities paying for disability-related expenses privately and their standard of living being affected in a discriminatory manner. Comment: Why should costs be covered by additional resource allocations? I suggest that costs associated with disability must be considered in the initial budgets of design and construction. It is important the inclusion of these costs in regular budget.

(Par. 91) ... It is important that the use of support of any kind is considered as disability-related extra expenses. Comment: Extra-expenses? I suggest deleting this word to avoid re-considering that it is about "exceptional situations". They must be considered as regular expenses for inclusion. Assistants should be free of paying entrance.

(Par. 92) Data and information should Comment: I suggest to replace by “must” be disaggregated systematically…

(Par. 94 l)

(l) Monitoring and implementation envisaged under article 19 should Comment: I suggest to replace by “must” be carried out in full consultation and participation of persons with disabilities through their representative organizations.

Comment to Par. 94: I suggest to incorporate that the fulfillment of these obligations must be assumed intersectorally by the SPs.