**Draft general comment on art. 19 UNCRPD**

**Submission by GRIP vzw**

GRIP, Gelijke Rechten voor Iedere Persoon met een handicap (Equal Rights for Every Person with a disability) is a civil rights organization for and of persons with a disability. We previously submitted a shadow report and sereral submissions concerning the implementation of the CRPD in the Flanders region of Belgium.

In the current submission we present a brief comment on the Draft General Comment no 5 - Article 19 – Living independently and being included in the community.

This comment is in line with the submission we made earlier, in preparation of the general day of discussion.

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**Appreciation for the work of the Committee on Article 19**

We would like to express our appreciation for the work of the Committee on Article 19. As Flanders achieves very high numbers of institutionalized adults and children with a disability, the ratification of the CRPD pushes the Flemish Government to pay more attention on the right to support to live and participate in the community. To prevent wrong interpretations of the CRPD art. 19, we are in great demand for more guidance from the Committee. The Draft presented by the Committee is very welcome and useful.

Yet we find some important issues that need to be cleared out, that are essential for a good clear uderstanding without any possible misinterpretation and for a good implementation of art 19.

**Paragraph 15** :

* Can the Committee specify in the definition of independent living that it implicates having the necessary support to your needs because of the disability  so that you don’t depend on your family and volunteers ? In this context it would be useful to describe the difference between usual support needs a person may have for example because of a temporary situation such as a broken leg, and the extra structural support needs because of the disability . Can the Committee also make clear what the responsibility of the states is to finance this extra support ?
* Can the Committee specify in the definition of ‘independent living’ whether it implicates the control regarding the support he or she needs for participation ?
* Can the Committee make clear if an organization offering assistance organized in a collective way, is not « personal assistance » ?
* Can the Committee please specify that any options for personal assistance without interference from intermediate organizations should not be more expensive nor get less financing? This is important to protect the option to organize your support independently from collective organizations.
* Can the Committee specify how far reaches the concept of institutionalization as a situation of limited freedom of choice ? Does it also mean you don’t have the major control about who assists you, when, how, where and for which tasks?
* In a situation where a person’s choices to participate are limited because he or she is not given control over the support / assistance he or she needs, does the Committee consider this a situation of institutionalization ?
* Can the Committee please add education and work as important domains for community living and write a line about the right to fulfill social roles and live the same independence in their social relationships compared to other citizens?
* Can the Committee add definitions of inclusion, segregation, isolation, exclusion and integration ? In GRIP we define inclusion as follows : Inclusion is the right to full participation in society on an equal base with other citizens, an independent life with equal opportunities and respect for individual choices ?

**Paragraph 16 :**

* Can the Committee please reformulate last three sentences of this paragraph? They are very important but formulation is confusing and, in our view, problematic for a good interpretation of CRPD art 19.

Regarding the formulation: “Residential services, where housing and support are delivered in one package (…)” :

In our interpretation of CRPD, art 19b is about support services and art. 19c is about community services. Community *services (19c) are services destinated to everyone and are the places and atmospheres where participation in the community takes place.* Support services (art 19b) are services to support people with support needs / people with a disability to live and participate in the community or in these places / community services.

* *We suggest to distinguish these two categories consequently, which would avoid confusion. So we suggest to talk about “residential* ***support*** *services” and not about “residential services”.*

The description of residential support services in this paragraph 16 with a similar description in paragraph 28, is highly problematic and in our view, a misunderstanding of the meaning of this term is the origin of most of the confusions about the meaning and purpose of art 19.

Delivering housing and support in one package can only be linked to ‘institutions’ and not to ‘residential support services’, we think.

Article 19b talks about a range of “in-home, residential and other community support services”. So is art 19 talking about residential services or residential support services? We consider it contradictory and problematic that residential support services would be translated as arrangements where housing and support are delivered in one package, and at the same time having art 19b telling the state to offer this kind of service. The link between support and housing is the core of institutionalisation and the CRPD would promote to perpetuate it?

The statement in article 28 about offering residential services in a transition period, as a temporarily measure is not useful in this context but instead weakening art 19. There is no indication of temporarity or transition integrated in the tekst of the article 19. Why then for instance not question the formulations about personal assistance, could some critics argument? Personal assistance should also be temporarily?

Of course there is an important question to be answered about what to do with thousands of people living in institutions and how to deinstitutionalize from their own perspective and possibilities. We would advice to separate carefully explanations about the content, the purpose and the meaning of art 19 on one hand, and comments on implications for the transition process on the other hand. Additionally comments for the transition process should be coherent to the content and purpose and principles of CRPD itself.

Two guidelines must prevail in the transition process: prevent new institutionalization and create conditions for institutionalizated people to change their lives.

* Therefore we think that the Draft General Comment, in a paragraph on transition, should clearly forbid new government investments in institution.
* It should also write down that governments budgets from places in institutions that come free, should be changed to individualized community services.
* So we suggest the Committee to formulate a more coherent description of he meaning of “residential support services” for example as follows: residential support services (art 1b) are support services that are given in the community where the person resides in that moment.
* We suggest a broad view on the term ’residing’, which can be understood as ’to be somewhere’ and therefore includes ‘being at school’, ‘being on your way to some place’, being at the sports club, being a week in the hospital, visiting a familiy member, being in a holiday spot, etc.

All those places are not ‘home’, yet support services should be available if the person needs it in another place than ‘home’. It is absolutely logica and necessary this is mentioned in art 19b. If not, art 19b would only give examples about support given at home and not in society.

Institutions / residential care settings where the person most of the time resides is the opposite of individualized residential support services, providing support in the community. So we would advice to clear this out and check the tekst of the Draft General Comment on this.

* For paragraph 16, we would advice to replacet he term “residential services” by “institutions”
* The second last sentence of paragraph 16 is confusing. Independent living and community living cannot be counted as personal assistance because it’s different types of things, we think : the first two concepts are the aim, and the latter an essential tool. “Maybe the Committe would mean :  « if assistance is only provided for a group of people within certain arrangements such as group homes, it is not personal assistance. »
* Fot the masts entence of paragraph 16, we would write : « institutionalized settings where right to assistance depends on choices and needs of other persons with a disability, are not compliant with the concepts of independent and community living »

**paragraph 25 :**

* Can you add two important situations in which there is also a lack of options to choose for ?

1/ when the way to an institution is easier than the way to personal assistance to live in society, and

2/ when a long period on a waiting list for assistance affects the possibilities and motivation to keep on living in society ?

**Paragraph 40e**

The concept of « community based services » is not brought up in the CRPD but appears in paragraph 40 of the draft general comment on art 19. As we interprete paragraph 40e, this is referring to art 19c talking about community services and facilities for the general population.

* We suggest the Committee to use the same concepts as used in CRPD art 19 to avoid confusion. In our view, « community services » (services for the community, where participation happens), is clear enough. It is clear enough that community services have their place in the community (are based in the community). The term « community based services » can more easily be interpreted as « special services for people with a disability, given in the community ». But in art 40e  we think the Committee refers to general facilities, so « community services ».

**Paragraph 47 : “Freedom of choice” for segregation, isolation, exclusion and limitated personal autonomy ?**

Paragraph 47 of the draft general comment says: “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.”

**We want to express our enormous concern about this paragraph 47 that, in our opinion, reframes art.19 and undermines the implementation of the right of inclusion.**

We find this paragraph in contradiction with the principle of CRPD. Institutions are systems that limit personal freedom, choices and autonomy to a severe extent. It is contradictory to stress the right to personal autonomy on an equal base as persons without a disability, and at the same time focus on the right to live in settings set up especially for persons with a disability characterized by a limited personal freedom and autonomy.

The first sentence is in contradiction with paragraph 25 or is at least not considering the overall reality that is very well explained in paragraph 25: people with a disability go to institutions because there is not enough care and support to live in societies. Without the necessary support and care, some people with a disability die within minutes, hours, days or weeks. So they are obliged by these circumstances to ask for an institution. Is this a free choice? No, this is a direct consequence of the lack of an alternative to live in society. So, when focusing on a theoretical right to “choose for an institution” the Committee is not taking into account the reality and context that is the origin of the CRPD itself.

The second phrase of paragraph 47 is not clear enough about what states should and shouldn’t do to go forward to an inclusive society where all people with a disability are included.

for example the sentence “does not correspond with a states’ party duty to maintain institutions or to ensure the availability of residential support services”

* Does the committee mean it is **forbidden** to states to further provide and **finance** institutions? If yes, can the committee please make that more clear?

This second phrase is not clear either in the use of the concepts. As explained in another part of this submission, residential support services can’t be seen as institutionalized care settings since it would be contradictory for the CRPD promoting it in art 19b, talking about individualized support services that make inclusion and personal autonomy possible. We strongly advice the Committee to avoid placing “residential support services” in the same category as “institutions”.

* This paragraph 47 is very confusing for us and changing the content of article 19. We suggest the Committee to remove it.

Paragraph 47 refers particularly to art 19 a CRPD and the choice to live where and with whom people with a disability want to live. But art. 19a follows on the main part / first lines of article 19. These first lines define the frame in which, in our view, the following parts of the article must be read. This frame is, without any doubt, the right to live IN the community.

* Can the Committee please explain how we can start talking about the choice to be institutionalized that is to say to be isolated and segregated (interpretation of art 19a by the draft general comment) in order to achieve the goal of the right to live IN the community?

We can’t understand why the draft general comment suddenly talks about the individual freedom of choice for segregation and isolation (which is the case for living in institutions).

* Can the Committee explain if this is an important general human right? Is this a particular right of people with a disability?

Which individual would freely choose to isolate itself from society when he or she has got the real possibility to take part and be respected in an inclusive society? Maybe in some exceptional cases some person would freely choose this particular way of living, as a few people without a disability also choose to live alone in the wood, or stick together in a commune. But on the whole people want to be part of society. Does the Committee want to make guidelines about exceptional cases? People with a disability are not different from other human beings: they want to belong to society. The CRPD was made to protect this right and change a situation of violation of these rights. The numerous cases where people with a disability seem to ‘choose’ for an institutional life are characterized by the lack of real alternatives. Instead of writing down an ‘overall human right to choose for segregation and isolation’, or focus on a highly philosophical and random issue, it would be more helpful for a proper interpretation to stick to the text and the important purpose of article 19.

* Can the Committee explain whether the right to live isolated and segregated from the rest of society is an important general human right, protected by human rights treaties? Is it a particular right for people with a disability? Can the Committee explain carefully why she focuses on this issue, being aware of the whole context of institutionalization and reality of lack of alternatives and direct or smooth stimulation for people with a disability to ask for an institution?
* Can the Committee focus on the concept of “being obliged to”, which in our view is also the case when there are no real and equal alternatives available?
* Related to the use of the term ‘imposition’ of certain living arrangement in paragraph 15c, what is the meaning of imposition? It might be clearer to say that living in an arrangement where support is shared with other people is institutionalizing people.

The framework of the CRPD, same as for other Human Rigts Treaties, is made to urge states to provide policy to prevent exclusion, segregation, isolation, and inequality. We consider paragraph 47 as a severe threat to the realization of this aim and therefore as a severe threat to the CRPD’s impact in the future. We are sure this paragraph will be used by states to stimulate segregation and exclusion using the ‘right of freedom of choice’. We don’t know if the Committee is fully aware of her enormous responsibility when leaving paragraph 47 in this General Comment.

* We ask the Committee to be fully aware of the additional difficulties paragraph 47 creates for human rights organizations to use CRPD as mandatory guidelines towards the right to inclusion. We wouldstrongly advice to remove this paragraph from the General Comment.

**Collective versus individualized support**

We miss an explanation about the a vision of the committee is regarding the legitimacy of financing directly *collective* care organizations, guaranteeing a big capacity, accesibility and power to these collective care organizations.

***Our experience*** is that collective care organizations are not able to provide individually suited support to many persons with a disability. There is a lack of flexibility that we think is inherent to the collective character of these organizations.

**This goes for all kind of collective care or supports organizations,** including day care centers, residential institutions, specialized or regular organizations providing care at home,…

Collective organizations decide which individual is cared for first, decide which care giver will be with which individual at what time. In this way the person is placed in and should fit in a care giving system where the needs can only be answered in a way that fits for the organization.

This results often in a ***violation*** of the right of dignity and does not meet the need and the right to suitable support for full participation. States stimulate, this way, the dependence on collective organizations as well as the competition between persons with a disability.

As this affects also the personal dignity, this is an ***ethical question*** : Is it legitimate for a state to finance collective care organizations who cannot provide individually suited support to people, with the consequence of making participation and a life in dignity more difficult? Is this legitimate while the person with a disability has no possibility to choose for a better alternative, by controlling at least the management and / or financing of his / her own support?

***Our view*** is that states should change the financing system of support, and changing direct financing of collective care organizations into direct payment to individuals with a support need. Existing collective care can only be financed by states in a time framed transition period for the persons who receive it already.

* Can the Committee give clarity and arguments about this ? Does the committee share our view on financing collective care and support organizations ? If not, which frame does the committee use on this ?
* Viewing this topic from the other side, could the Committee deepen about the responsibility of the states to take enough actions to enhance the accessibility of individualized support, such as personal assistance*?*

**Paragraphs 59 – 60 – 61 : Unconditionality of rights according the individual supports needs and extra disability-related expenses**

**Paragraph 59** :

* Can the Committee affirm that the assessment for elegibility for access to support can not take into account the presence or strength of the social network of the person. Can the Committee affirm that also income of the person or his relatives can not be taken into account in the support-need-assessment and decision to obtain support ?

**Paragraph 60 - 61 :**

It is not so clear what kind of cash transfers the Committee means. Dependent from the character of the particular cash transfer, guidelines can be different. It would be more useful if different kinds of cash transfers could be described. Some cash transfers are about income for living, that might be more the topic in art.28. These cash trensfers can be disability specific, or designated to a larger group of the population. Some cash transfers are about extra expenses related to the disability but difficult to measure. Some cash transfers are about assistance devices and adaptations to houses. Some cash transfers are about support and assistance. Cash transfers for assistance devices, adaptations, support and assistance can be defined as direct payment systems. This is important for a good interpretation of the guidelines about these different cash transfers.

* Can the Committee describe what she means by « cash transfers », in order to avoid confusion between direct payment budgets for support and assistance ?
* Can you describe that cash transfers meant for support should not be a fixed amount of money but earmarked personal budgets high enough to pay support costs due to the disability?

Art 61 is in contradiction with the rest of the Draft General Comment and with the CRPD itself. CRPD is about human rights on an equal base with others. Art 61 introduces the possibility to limitate these absolute human rights. Art 61 legitimates conditionality and prioritization to access to cash transfers without specifying which conditions this is about. This is very confusing for us.

In Flanders there are long waiting lists for support and a system of prioritization with a lot of conditions was made to select who is most needing a personal assistance budget. This is defining who gets support. This system is criticized as highly subjective and discriminatory towards people living inclusively.

* We recommend to take away paragraph 61. If not, can the Committee be more specific on which conditions she finds legitimate to put limitations to cash transfers, necessary to pay support or assistance, or assistance devices or adaptations to homes, or disability related extra expenses, or income for living expenses (although more a subject of art.28) ?

**Paragraph 83 :**

* Can the Committee clear out if a states party can impose mandatory visits by a state officer in the person’s home as a condition to receive personal assistance ? Can this be seen as a violation of the right of personal privacy that can’t be allowed ?

**Paragraph 92 :**

* Can the Committee add the importance of more qualitative information for example about choice and control of the support, and recommend data about appreciation by persons with a disability about access, choice and control to support to live independently and fully participate in society ?

**Paragraph 94 c :**

The right to independent living and community living is conditioned by the right to support or personal assistance. Some people with a disability are left out by the system of support financing. In some countries the rights are merely theoretical rights because of long waiting lists.

* Can you clear out if the states have to guarantee the right to support / personal assistance by law ?
* Can you specify the rights for independent living, community living and support and assistance are rights of ALL people with a disability?
* Can you specify that reasonable waiting times should be introduced and respected in states with long waiting lists?

**Paragraph 94 d :**

* Can the Committee also add special attention for children at risk to be institutionalized by lack of support in the community ?
* Can the Committee please add the need to finance organizations independent from service providers to stand beside the persons with a disability who need support to make decisions?
* Can the Committee please add the importance of peer counseling in the process of making choices about your life and support. States should support peer counseling actively.

**Paragraph 94 f :**

* Does the Committee mean participation at the level of support services, at the level of community services, at the level of politics, or the three of them?
* To have a real influence of people with a disability regarding the professionals, participation at the level of support services should be very substantial. Can the Committee be more concrete on this?
* Can the Committee include the participation of individual persons with a disability, since they often have an additional very helpful and authentic view that is not interfered so much by certain strategies of representatives of disability organizations.

**Additional recommendation:**

* Can the Committee add the principle that in the process of implementing art 19 persons with a disability should not lose their level of social protection, including cash benefits, the amount of support they get, the existing choice and control over the support?