

# Comments on the Draft General Comment on article 19 of the Convention on the Rights of Persons with Disabilities: Living independently and being included in the community.

## Submitting organisation

The Swedish Disability Rights Federation

The Swedish Disability Rights Federation is an umbrella organisation for 41 organisations of persons with disabilities, together representing approximately 400 000 persons. The work of the Federation is based on human rights and its goal is an inclusive society.

A major part of the comments has been drafted in cooperation with the Independent Living Institute, a project-based policy and competence development center that works with promoting self-determination for people with disabilities.

## General remarks

The Swedish Disability Rights Federation finds the Draft General Comment on article 19 important and timely. The general direction emphasised by the draft to move towards a human rights-based model founded on self-determination is most needed and welcome. It is important to reiterate that the right to live independently means exercising freedom of choice and control over decisions with the same level of self-determination and interdependence for all members of society, without prejudice to certain cultural norms or values.

In relation to other articles in the Convention, we particularly welcome the emphasis on article 12 and the right to full enjoyment of legal capacity. Without equal recognition before the law, the right to independent living would be an illusion. Similarly, formal equal recognition before the law would be an illusion without independent living in the community. Transforming communities through parallel processes, including universal design, awareness-raising, guaranteeing strong protection against discrimination, and allowing individual needs-based forms of service, such as personal assistance, is rightly recognised by the Convention and the Draft General Comment on Article 19.

We would like to strongly endorse paragraphs 40 (c) and 53 of this draft. Living independently in the community is impossible, must never entail dependence on informal support from family and friends. States parties must not evade their responsibilities by passing them onto the families of persons with disabilities, either formally or informally by not providing required support.

We would furthermore like to emphasize the importance of paragraphs 19, 27, 29, 57-59, 62-63, 74 and 91.

## Proposed amendments

### Paragraph 3

Rationale: To further align the text with the general principles in the convention:

“... and respect for the evolving capacities of children with disabilities *and respect for the rights of children with disabilities* to preserve their identity (art. 3 (h)).”

### Paragraph 15 c)

Rationale: To underline the difference between independent living and having limited influence over the work that staff carry out in an institutional setting:<sup>1</sup>

“(c) Both concepts, i.e. independent and community living, refer to **life settings outside of institutions**, ~~including large or smaller group homes~~. Institutionalization is not about living in a particular setting, it is, first and foremost, about losing control as a result of the imposition of a certain living arrangement. Therefore, neither large scale institutions with more than a hundred residents nor smaller ~~group homes ones~~ with five to eight individuals can be called independent living or community living arrangements. Although institutionalized settings can differ in size, name and setup, there are certain defining elements, such as isolation and segregation from community life, lack of control over day-to-day decisions, lack of choice ~~about~~ ~~over~~ whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, *forced dependence on staff who are shared by other residents and no or limited influence over whom one has to accept assistance from*, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment.”

### Paragraph 15 (d)

Rationale: To reassure that economic reasons are not legitimate to justify insufficient allocations of finances to personal assistance as a form of service. Doing so would undermine independent living in practise:

“... It is based on an individual needs assessment and a person/user’s life circumstances. *Methods of assessing individual needs may be incompatible article 17. The rates allocated to persons with disabilities for personal assistance need to be in line with the current salary rates in each country. Enough resources need to be allocated to cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.* The service is led by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer...”

### Paragraph 18

Rationale: To emphasize the right to support to carry out daily life activities:

“Whereas the right to independent living refers to an individual dimension, i.e., the place of residence, lifestyle, *daily life activities* and most importantly...”

### Paragraph 25

Rationale: Delete group homes to avoid confusion with other concepts.

“Often, persons with disabilities cannot exercise choice because there is a lack of options to choose from. This is the case, for instance, if informal support by the family is the only option, if support is

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<sup>1</sup> Office of the United Nations High Commissioner for Human Rights: Thematic study on the right of persons with disabilities to live independently and be included in the community (A/HRC/28/37), para. 21.

unavailable outside of institutions, if housing is inaccessible or support is not provided in the community and when support is only provided within specified forms of residence *like group homes or institutions.*”

### **Paragraph 29**

Rationale: Recreation is missing

“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, *as well as travel and recreation.*”

### **Paragraph 35**

Rationale: To increasingly emphasise universal design and the removal of disabling structures in residential buildings and consistency with wording in general comment 2.

“... Access to housing means having the option to live in the community just like persons without disabilities. Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that *many* people with disabilities *must have to* live in the same building, complex or neighbourhood. Accessible housing, providing accommodation to persons with disabilities, who live as singles or as a part of a family, must be available in sufficient number, *within all areas of the community throughout the community*, to *ensure provide* the right and possibility for persons with disabilities to choose from. *To this end, universal design of residential new construction and plan accessibility for retrofitting of existing residential structures are required.* In addition, housing must be *made* affordable to persons with disabilities, which often means *individual subsidies*, *since as* persons with disabilities tend to have *lower than average less income* compared to others.”

### **Paragraph 38**

Rationale: Only time “key elements” occurs. Could be mixed up with paragraph 40 with six “core elements.”

Proposal: Clarify which the other two key elements are.

### **Paragraph 40 d)**

Rationale: Consistency with paragraph 62 (personalisation) and paragraph 70 (specific services) as well as wordings and content in general comment 2 and 4.

Proposal: Clarify human-rights based disability specific services or use other terminology.

### **Paragraph 41**

Rationale: A civil rights dimension is missing in relation to accessibility in article 19 c:

Proposal: Add civil right dimension in relation to article 19 c, as it covers access to / accessibility.

### **Paragraph 47**

Rationale: Paragraph 47 is ambiguous and not consistent with paragraph 15 c) and 28.

Self-determination is fundamental to independent living. In paragraph 15 a) the committee states that living independently does not necessarily mean living alone. States parties must not decrease, limit or abstain from implementing support services for individuals wishing to live alone limit inclusion in society, control over day-to-day decisions and choice over whom to live with.

As "particular living arrangements" are phased out progressively, individual support services in the community, such as personal assistance or other forms of user-led-support, and barrier-free housing in

existing housing stock and new residential construction are to be phased in to make institutionalization unnecessary. To this end, State Parties are to issue comprehensive plans with specific targets, timetable, budget and monitoring mechanisms including sanctions for non-compliance.

The individual's dependence on and the individual's lack of control over the shared staff, not the number of persons with disabilities in the particular living arrangement – one, two or more persons – are the decisive criteria in the operational definition of a residential institution.

Residents of existing institutions are to be offered information and advice as well as trial periods with support and training of several different community-based alternatives. Residents who still do not want to move, shall not be forced to leave institutional settings. The individual informed choice, with supported decision-making if wanted and needed, and free from any undue influence, must be decisive on the choice of living arrangements.

Proposal for new text:

*“Persons with disabilities must have the right to choose to live by themselves or together with other persons without or with disabilities. Regardless of whether an individual lives alone or together with other persons, State parties are responsible for providing the individual with a disability with the quantity and quality of individualized support services that enable the individual to live independently and in self-determination in the community pursuing one's interests, exercising one's rights and fulfilling one's duties as citizen. The right to decide where, how and with whom to reside also embraces the decision to live in institutional 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*~~

*Residents who make the choice not to move, shall not be forced to leave the residence they have chosen. The individual informed choice, with supported decision-making if wanted and needed, and free from any undue influence, must be decisive on the choice of living arrangements. Furthermore, the choice to live with others must not affect the possibilities of adequate funding.*

## **Paragraph 64**

Rationale: Officers and decision-makers involved in assessment of individual support needs are missing.

“States should ensure that professionals, *including staff, decision-makers and civil servants monitoring services for persons with disabilities*, are adequately trained on independent and community living. In certain contexts, professional training is essential in order to ensure that support is provided according to the standards of the Convention and respects the individual's will and preferences.”

## **Paragraph 67**

Rationale: Access to legal aid is missing.

“States parties should ensure access to justice and provide *legal aid*, appropriate legal advice, remedies and support, including through reasonable and procedural accommodation for persons with disabilities who seek to enforce their right to independent and community living.”

### **Paragraph 73**

Rationale: Parents with disabilities are missing

“It is also important to provide support, information and guidance to families (art. 23) to prevent institutionalization of children with disabilities and to have inclusive policies on adoption to ensure equal opportunities to children *and parents* with disabilities. *It is furthermore important to provide parents with disabilities with necessary support to facilitate their child-rearing responsibilities.*”

### **Paragraph 78**

Rationale: To emphasize the need of persons with disabilities to live in the community in order to be able to realize their rights enshrined in Article 12:

“... it is imperative that persons with disabilities have the opportunity to develop and express their will and preferences in order to exercise their legal capacity on an equal basis with others. To achieve this, they have to be a part of the community *and have to be ensured access to mainstream as well as personalized community-based services.* Accordingly, support in the exercise of legal capacity should be provided by using a community-based approach which respects the will and preferences of individuals with disabilities.”

### **NEW Paragraph AFTER 78**

Rationale: New paragraph needed concerning article 13

*“Access to justice is fundamental to ensure full enjoyment of the right to independent and community living. States parties must ensure that all persons with disabilities have legal capacity and standing in courts. States parties must furthermore ensure that all decisions concerning independent and community living may be subject to appeal. Support to enable independent and community living shall be justiciable as rights and entitlements. To ensure equal and effective access to justice substantial rights to legal aid, support and reasonable accommodation are essential.”*

### **NEW paragraph after 80**

Rationale: New paragraph needed concerning article 17.

*“Article 17 is intrinsically linked with article 19. The right to independent and community living must be ensured in a manner that fully respects the physical and mental integrity of persons with disabilities. This include autonomy, the right to make one’s own decisions, as well as freedom from intrusive and offensive methods for needs’ assessments.”*

### **Paragraph 84**

Rationale: Parents with disabilities are missing

“; the rights enshrined in article 23 of the Convention are essential to prevent children from being taken away from their families and being institutionalized as well as to support families in community living. *These rights are equally important to ensure that children are not taken away from their parents due to the latter’s disability.* States parties should provide information, guidance and support to families in upholding *the rights of children and parents with disabilities, including user led personal assistance,* and promote inclusion and participation in the community so that families are in a better position to contribute to independent and community living.”

## **Paragraph 85 and 87**

Rationale: To strengthen the position of habilitation in connection with rehabilitation.

“85. Independent and community living are inherently linked to inclusive education (art. 24), health care (art. 25), *habilitation and* rehabilitation (art. 26) and work and employment (art. 27). Inclusive education (art. 24) requires recognition of the right of persons with disabilities to live independently and enjoy inclusion and participation in the community.

87. There is interdependence between independent and community living, *and habilitation and* rehabilitation (art. 26). For some persons with disabilities, participation in *habilitation and* rehabilitation services is not possible if they do not receive sufficient individualized support. At the same time, the purpose of rehabilitation is to enable persons with disabilities to participate in the community. *Habilitation and* rehabilitation is dominantly relevant in relation to education, employment, health and social matters.”

## **Paragraph 94 (c)**

Rationale: To ensure that the rights under article 19 are effective, and not theoretical and illusory in the jurisdictions of the states parties, especially given the purpose of article 4 paragraph 1 a):

“(c) Provide persons with disabilities with substantive and procedural rights to independent living and community living, *including providing effective remedies that the individual can use for redress if the rights under article 19 are violated;*”

## **Paragraph 94 (g)**

Rationale: To ensure that the sanctions for improving accessibility are effective in practise:

“(g) Design clear and comprehensive legislative and policy guidelines and allocate sufficient financial resources for the construction of accessible housing units, public buildings and public spaces and transport along with an adequate time frame for their implementation and sanctions *which are effective, deterrent and proportionate* for violations by public or private authorities.”

On behalf of the Swedish Disability Rights Federation

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