



Convention on the Rights of Persons with Disabilities

Distr.: General
27 October 2017

Original: English

Committee on the Rights of Persons with Disabilities

General comment No. 5 (2017) on living independently and being included in the community

I. Introduction

1. Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed. Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation.

2. Article 19 of the Convention on the Rights of Persons with Disabilities recognizes the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives. The foundation of the article is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth.

3. Article 19 emphasizes that persons with disabilities are subjects of rights and are rights holders. The general principles of the Convention (art. 3), particularly respect for the individual's inherent dignity, autonomy and independence (art. 3 (a)) and the full and effective participation and inclusion in society (art. 3 (c)), are the foundation of the right to live independently and be included in the community. Other principles enshrined in the Convention are also essential to interpret and apply article 19.

4. Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities be in line with universal design principles.

5. In the preamble to the Convention, States parties recognize that many persons with disabilities live in poverty and stress the need to address the impact of poverty. The cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalization of persons with disabilities. Policies and concrete plans of action for social inclusion of persons with disabilities, including through the promotion of their right to independent living (art. 19), represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.

6. The present general comment aims at assisting States parties in their implementation of article 19 and fulfilling their obligations under the Convention. It concerns primarily the obligation to ensure every individual's enjoyment of the right to live independently and be included in the community, but it is also related to other provisions of the Convention.



Article 19 is one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral to the full implementation of the Convention.

7. Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights enshrined in this norm are fulfilled. International human rights law imposes obligations which are of immediate effect and others which may be realized progressively.¹ Full realization also requires structural changes that may need to be taken in stages, whether civil and political or social, economic and cultural rights are at stake.

8. Article 19 reflects the diversity of cultural approaches to human living and ensures that its content is not biased towards certain cultural norms and values. Living independently and being included in the community is a basic concept of human living around the globe and is applied to the context of disability. It means exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society. This right must be effectively realized in different economic, social, cultural and political contexts. The right to live independently and be included in the community refers to all persons with disabilities, irrespective of race; colour; descent; sex; pregnancy and maternity; civil, family or carer situation; gender identity; sexual orientation; language; religion; political or other opinion; national, ethnic, indigenous or social origin; migrant, asylum-seeking or refugee status; belonging to a national minority, economic or property status; health status; genetic or other predisposition towards illness; birth and age, or any other, status.

9. The right contained in article 19 is deeply rooted within international human rights law. The Universal Declaration of Human Rights stresses in article 29 (1) the interdependence of an individual's personal development and the social aspect of being a part of the community: "Everyone has duties to the community in which alone the free and full development of his personality is possible." Article 19 has its roots in civil and political as well as economic, social and cultural rights: the right to liberty of movement and freedom to choose one's residence (article 12 of the International Covenant on Civil and Political Rights) and the right to an adequate standard of living, including adequate clothing, food and housing (article 11 of the International Covenant on Economic, Social and Cultural Rights), and to basic communication rights form the basis for the right to live independently and be included in the community. Liberty of movement, an adequate standard of living as well as the ability to understand and have one's preferences, choices and decisions understood form indispensable conditions for human dignity and the free development of a person.²

10. The Convention on the Elimination of All Forms of Discrimination against Women emphasizes the equality of women and men and condemns discrimination against women in all its forms (art. 1). The Convention reaffirms the equality between women and men concerning legal matters, including legal capacity and opportunities to exercise that capacity (art. 15 (2)). It also requests States parties to recognize the same rights with regard to the law relating to the movement of persons and the freedom to choose their residence and domicile (art. 15 (4)).

11. Article 9 (1) of the Convention on the Rights of the Child requires States parties to "ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interest of the child". States parties to this Convention "shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities", as guaranteed by article 18 (2). In addition, article 20 (1) establishes that "[a] child temporarily or

¹ See Committee on Economic, Social and Cultural Rights, general comment No. 3 (1990) on the nature of States parties' obligations 3, paras. 1-2.

² See Universal Declaration of Human Rights, art. 22; Human Rights Committee, general comment No. 27 (1997) on freedom of movement, para. 1; Committee on Economic, Social and Cultural Rights, general comment No. 4 (1991) on adequate housing, para. 7.

permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State”, and article 20 (2) that “States parties shall in accordance with their national laws ensure alternative care for such a child”. Alternative care provided on the grounds of disability would be discriminatory.

12. Article 23 (1) further establishes that all children with disabilities should enjoy a life in dignity in conditions which ensure self-reliance and facilitate active participation in the community. The Committee on the Rights of the Child has expressed its concern at the high number of children with disabilities placed in institutions and urged States parties, through deinstitutionalization programmes, to support their ability to live in their family, extended family or foster care.³

13. Equality and non-discrimination are fundamental principles of international human rights law and enshrined in all core human rights instruments. In its general comment No. 5 (1994) on persons with disabilities, the Committee on Economic, Social and Cultural Rights highlights that “segregation and isolation achieved through the imposition of social barriers” count as discrimination. It also stresses in relation to article 11 that the right to an adequate standard of living not only includes having equal access to adequate food, accessible housing and other basic material requirements, but also the availability of support services and assistive devices and technologies fully respecting the human rights of persons with disabilities.

14. Article 19 and the content of the present general comment must also guide and support the implementation of the New Urban Agenda adopted by the United Nations Conference on Housing and Sustainable Urban Development (Habitat III) as an integral part of 2030 Agenda for Sustainable Development and the Sustainable Development Goals. The New Urban Agenda advocates a vision of cities and human settlements where all persons can enjoy equal rights and opportunities by promoting inclusive, just, safe, healthy, accessible, affordable, resilient and sustainable cities and human settlements. In connection with article 19 of the Convention, Sustainable Development Goal target 10.2, empowerment and promotion of social, economic and political inclusion for all, and target 11.1, ensuring access to adequate, safe and affordable housing and affordable services for all, are of special importance.

15. The Committee on the Rights of Persons with Disabilities has noted advancements in implementing article 19 in the last decade. However, the Committee observes a gap between the goals and spirit of article 19 and the scope of its implementation. Some of the remaining barriers are the following:

- (a) Denial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements;
- (b) Inadequacy of social support and protection schemes for ensuring living independently within the community;
- (c) Inadequacy of legal frameworks and budget allocations aimed at providing personal assistance and individualized support;
- (d) Physical and regulatory institutionalization, including of children and forced treatment in all its forms;
- (e) Lack of deinstitutionalization strategies and plans and continued investments in institutional care settings;
- (f) Negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available assistance;
- (g) Misconceptions about the right to living independently within the community;

³ See Committee on the Rights of the Child, general comment No. 9 (2006) on the rights of children with disabilities, para. 47.

(h) Lack of available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;

(i) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of article 19, including the participation of representative organizations of persons with disabilities;

(j) Insufficient mainstreaming of disability in general budget allocations;

(k) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within the community in a State party.

II. Normative content of article 19

A. Definitions

16. In the present general comment the following definitions apply:

(a) **Independent living.** Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities;

(b) **Being included in the community.** The right to be included in the community relates to the principle of full and effective inclusion and participation in society as enshrined in, among others, article 3 (c) of the Convention. It includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them to be fully included and participate in all spheres of social life. These services can relate, among others, to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media. The right also includes having access to all measures and events of political and cultural life in the community, among others, public meetings, sports events, cultural and religious festivals and any other activity in which the person with disability wishes to participate;

(c) **Independent living arrangements.** Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not "just" about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and

segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice 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; 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. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family;

(d) **Personal assistance.** Personal assistance refers to person-directed/“user”-led human support available to a person with disability and is a tool for independent living. Although modes of personal assistance may vary, there are certain elements which distinguish it from other types of personal assistance, namely:

(i) Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualized services must not result in a reduced budget and/or higher personal payment;

(ii) The service must be controlled 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. Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without the full and free consent of the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community;

(iv) Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making.

17. Providers of support service often wrongly describe their service using the terms “independent” or “community living” as well as “personal assistance”, though in practice such services do not fulfil the requirements posed by article 19. Mandatory “package solutions” which, among other things, link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements are not in line with article 19. The concept of personal assistance wherein the person with disabilities does not have full self-determination and self-control are to be considered not compliant with article 19. Persons with complex communication requirements, including those who use informal means of communication (i.e., communication via non-representational means, including facial expression, body position and vocalization) must be provided with appropriate supports enabling them to develop and convey their directions, decisions, choices and/or preferences and have them acknowledged and respected.

B. Article 19, chapeau

18. Article 19 reaffirms non-discrimination and recognition of the equal right of persons with disabilities to live independently in the community. In order for the right to live independently, with choices equal to others, and be included in the community to be realized, States parties must take effective and appropriate measures to facilitate the full enjoyment of the right and the full inclusion and participation of persons with disabilities in the community.

19. The article covers two concepts, which are only clearly mentioned in its heading: the right to independent living and the right to be included in the community. Whereas the right to independent living refers to an individual dimension, as a right to emancipate oneself without being denied access and opportunities, the right to be included in the community entails a social dimension, i.e., the positive right to develop inclusive environments. The right as enshrined in article 19 covers both concepts.

20. Article 19 explicitly refers to all persons with disabilities. Neither the full or partial deprivation of any “degree” of legal capacity nor the level of support required may be invoked to deny or limit the right to independence and independent living in the community to persons with disabilities.

21. When persons with disabilities are assessed as requiring a high level of personal service, States parties often consider institutions as the only solution, especially when personal services are considered to be “too costly” or the person with disabilities is considered to be “unable” to live outside an institutional setting. Persons with intellectual disabilities, especially those with complex communication requirements, among others, are often assessed as being unable to live outside institutional settings. Such reasoning is contrary to article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements.

22. All persons with disabilities should be free to choose to be active and belong to cultures of their own choice, and they must have the same degree of choice and control over their lives as other members of the community. Independent living is not compatible with the promotion of a “predefined” individual lifestyle. Young persons with disabilities should not be forced to live in settings designed for elderly persons with disabilities and vice versa.

23. Persons with disabilities of all genders are rights holders and enjoy equal protection under article 19. All appropriate measures should be taken to ensure the full development, advancement and empowerment of women. Lesbian, gay, bisexual, transgender, queer and intersex persons with disabilities must enjoy equal protection under article 19 and therefore respect for their personal relationships. Furthermore, the right to live independently and be included in the community encompasses the protection of persons with disabilities belonging to any age group, ethnic group, scheduled caste or linguistic and/or religious minority, as well as migrant, asylum seeking and refugee persons.

C. Article 19 (a)

24. To choose and decide how, where and with whom to live is the central idea of the right to live independently and be included in the community. Individual choice, therefore, is not limited to the place of residence but includes all aspects of a person’s living arrangements: the daily schedule and routine as well as the way of life and lifestyle of a person, covering the private and public spheres, every day and in the long term.

25. Often, persons with disabilities cannot exercise choice because there is a lack of options to choose from. This is the case, for instance, where informal support by the family is the only option, where support is unavailable outside of institutions, where housing is inaccessible or support is not provided in the community, and where support is provided only within specified forms of residence such as group homes or institutions.

26. Further, persons with disabilities might not be allowed to exercise their individual choice owing to the lack of accessible information regarding the range of choices available

and/or to legal restrictions deriving from guardianship laws and similar legal norms or decisions which do not allow persons with disabilities to exercise their legal capacity. Even if no formal laws are in place, other persons, such as families, caregivers or local authorities, sometimes exercise control and restrict an individual's choices by acting as substitute decision makers.

27. Legal personality and legal agency are the bases for the realization of independent living within the community for persons with disabilities. Article 19 is, therefore, linked to the recognition and exercise of legal personality and legal capacity as enshrined in article 12 of the Convention and further explained in the Committee's general comment No. 1 (2014) on equal recognition before the law. Further, it is linked to the absolute prohibition of detention on the basis of disability as enshrined in article 14 and elaborated in the respective guidelines.⁴

D. Article 19 (b)

28. Individualized support services must be considered a right rather than a form of medical, social or charity care. For many persons with disabilities, access to a range of individualized support services is a precondition for independent living within the community. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences, and individualized support should be flexible enough to adapt to the requirements of the "users" and not the other way around. This places an obligation on States parties to ensure that there are sufficient numbers of qualified specialists able to identify practical solutions to the barriers to living independently within the community in accordance with the requirements and preferences of the individual.

29. Subparagraph (b) specifies various individualized services which fall within the category of support services. They are not restricted to services inside the home, but must also be able to be extended to the spheres of employment, education and political and cultural participation; empowering parenthood and the ability to reach family relatives and others; participation in political and cultural life; one's leisure interests and activities; and travel as well as recreation.

30. While individualized support services may vary in name, type or kind according to the cultural, economic and geographic specifics of the State party, all support services must be designed to support living within the community, preventing isolation and segregation from others, and must in actuality be suitable for this purpose. It is important that the aim of these support services be the realization of full inclusion within the community. Therefore, any institutional form of support services which segregates and limits personal autonomy is not permitted by article 19 (b).

31. It is also relevant to keep in mind that all support services have to be designed and delivered in a mode which supports the overall purpose of the norm: full, individualized, self-chosen and effective inclusion and participation, and living independently.

E. Article 19 (c)

32. Services and facilities mentioned in this section of the article are non-disability-specific support services and facilities for the general population in the community. They cover a wide range of services, such as housing, public libraries, hospitals, schools, transport, shops, markets, museums, the Internet, social media and similar facilities and services. These must be available, universally accessible, acceptable and adaptable for all persons with disabilities within the community.

33. Accessibility of community facilities, goods and services, as well as the exercise of the right to inclusive, accessible employment, education and health care are essential conditions for the inclusion and participation of persons with disabilities in the community.

⁴ Guidelines on the right to liberty and security of persons with disabilities (A/72/55, annex).

Various deinstitutionalization programmes have shown that the closure of institutions, regardless of their size and the relocation of inhabitants in the community, in itself is not enough. Such reforms must be accompanied by comprehensive service and community development programmes, including awareness programmes. Structural reforms designed to improve overall accessibility within the community may reduce the demand for disability-specific services.

34. In terms of material scope, article 19 covers access to safe and adequate housing, individual services and community facilities and services. Access to housing means having the option to live in the community on an equal basis with others. Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood. Accessible housing providing accommodation to persons with disabilities, whether they live alone or as a part of a family, must be available in sufficient number, within all areas of the community, to provide the right of persons with disabilities to choose and the possibility to do so. To this end, barrier-free new residential construction and the barrier-free retrofitting of existing residential structures are required. In addition, housing must be affordable to persons with disabilities.

35. Support services must be available within safe physical and geographical reach to all persons with disabilities living in urban or rural areas. They have to be affordable, taking into account persons living on low incomes. They also need to be acceptable, which means that they must respect standard levels of quality and be gender, age and culturally sensitive.

36. Individualized support services which do not allow for personal choice and self-control are not providing for living independently within the community. Support services provided as combined residential and support service (delivered as a combined “package”) are often offered to persons with disabilities on the premise of cost efficiency. However, while this premise itself can be rebutted in terms of economics, aspects of cost efficiency must not override the core of the human right at stake. Persons with disabilities should not be required by rule to share personal assistance and assistants; this should only be done with their full and free consent. The possibility to choose is one of the three key elements of the right to live independently within the community.

37. The right to equal support services corresponds with the duty to ensure the participation and involvement of persons with disabilities in processes related to facilities and services in the community, ensuring that they are responsive to specific requirements, are gender and age sensitive, and that they are available to allow for the spontaneous participation of persons with disabilities within the community. For children, the core of the right to live independently and be included in the community entails a right to grow up in a family.

F. Core elements

38. The Committee finds it important to identify core elements of article 19 in order to ensure that the realization of a standardized minimum support level sufficient to allow the exercise of the right to live independently and be included in the community is carried out by every State party. States parties should ensure that the core elements of article 19 are always respected, particularly in times of financial or economic crisis. These core elements are:

(a) To ensure the right to legal capacity, in line with the Committee’s general comment No. 1, to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment;

(b) To ensure non-discrimination in accessing housing, including the elements of both income and accessibility, and adopting mandatory building regulations that permit new and renovated housing to become accessible;

(c) To develop a concrete action plan for independent living for persons with disabilities within the community, including taking steps towards facilitating formal

supports for independent living within the community so that informal support by, for example, families is not the only option;

(d) To develop, implement, monitor and sanction non-compliance with legislation, plans and guidance on accessibility requirements for basic mainstream services to achieve societal equality, including participation by persons with disabilities within social media, and secure adequate competence in information and communications technologies to ensure that such technologies are developed, including on the basis of universal design, and protected;

(e) To develop a concrete action plan and take steps towards developing and implementing basic, personalized, non-shared and rights-based disability-specific support services and other forms of services;

(f) To ensure non-retrogression in achieving the content of article 19 unless any such measures have been duly justified and are in accordance with international law;

(g) To collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions;

(h) To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.

III. Obligations of States parties

39. The obligations of States parties must reflect the nature of human rights as either absolute and immediately applicable (civil and political rights) or progressively applicable (economic, social and cultural rights). Article 19 (a), the right to choose one's residence and where, how and with whom to live, is immediately applicable as it is a civil and political right. Article 19 (b), the right to access individualized, assessed support services, is an economic, social and cultural right. Article 19 (c), the right to access service facilities, is an economic, social and cultural right, as many mainstream services, such as accessible information and communications technologies, websites, social media, cinemas, public parks, theatres and sports facilities, serve both social and cultural purposes. Progressive realization entails the immediate obligation to design and adopt concrete strategies, plans of action and resources to develop support services as well as making existing, as well as new, general services inclusive for persons with disabilities.

40. The obligation to respect does not only have a negative aspect; its positive aspect requires States parties to take all necessary measures to ensure that no rights enshrined in article 19 are violated by the State or by private entities.

41. In order to achieve the progressive realization of economic, social and cultural rights, States parties must take steps to the maximum of their available resources.⁵ These steps must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means.⁶ The systematic realization of the right to independent living in the community requires structural changes. In particular, this applies to deinstitutionalization in all its forms.

42. States parties have the immediate obligation to enter into strategic planning, with adequate time frames and resourcing, in close and respectful consultation with representative organizations of persons with disabilities, to replace any institutionalized settings with independent living support services. The margin of appreciation of States parties is related to the programmatic implementation, but not to the question of replacement. States parties should develop transitional plans in direct consultation with persons with disabilities, through their representative organizations, in order to ensure full inclusion of persons with disabilities in the community.

⁵ See article 2 (1) of the International Covenant on Economic, Social and Cultural Rights and article 4 (2) of the Convention on the Rights of Persons with Disabilities.

⁶ See Committee on Economic, Social and Cultural Rights, general comment No. 3, para. 2.

43. When a State party seeks to introduce retrogressive measures with respect to article 19, for example, in response to an economic or financial crisis, the State is obliged to demonstrate that such measures are temporary, necessary and non-discriminatory and that they respect its core obligations.⁷

44. The duty of progressive realization also entails a presumption against retrogressive measures in the enjoyment of economic, social and cultural rights. Such measures deprive people with disabilities of the full enjoyment of the right to live independently and be included in the community. As a matter of consequence, retrogressive measures constitute a violation of article 19.

45. States parties are prohibited from taking retrogressive measures with respect to the minimum core obligations of the right to live independently within the community as listed in the present general comment.

46. States parties are under an immediate obligation to eliminate discrimination against individuals or groups of persons with disabilities and to guarantee their equal right to living independently and participation in the community. This requires States parties to repeal or reform policies, laws and practices that prevent persons with disabilities from, for example, choosing their place of residence, securing affordable and accessible housing, renting accommodation or accessing such general mainstream facilities and services as their independence would require. The duty to provide reasonable accommodation (art. 5 (3)) is also not subject to progressive realization.

A. Obligation to respect

47. The obligation to respect requires States parties to refrain from directly or indirectly interfering with or in any way limiting the individual exercise of the right to live independently and be included in the community. States parties should not limit or deny anyone's access to living independently in the community, including through laws which directly or indirectly restrict the options of persons with disabilities to choose their place of residence or where, how and with whom to live, or their autonomy. States parties should reform laws that impede the exercise of the rights enshrined in article 19.

48. The obligation also requires States parties to repeal and refrain from enacting laws, policies and structures that maintain and create barriers in access to support services as well as to general facilities and services. It also entails the obligation to release all individuals who are confined against their will in mental health services or other disability-specific forms of deprivation of liberty. It further includes the prohibition of all forms of guardianship and the obligation to replace substituted decision-making regimes with supported decision-making alternatives.

49. To respect the rights of persons with disabilities under article 19 means that States parties need to phase out institutionalization. No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents' physical safety. Institutions should not be extended, new residents should not enter when others leave and "satellite" living arrangements that branch out from institutions, i.e., those that have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established.

B. Obligation to protect

50. The obligation to protect requires States parties to take measures to prevent family members and third parties from directly or indirectly interfering with the enjoyment of the right to live independently within the community. The duty to protect requires States parties

⁷ Letter dated 16 May 2012 addressed by the Chairperson of the Committee on Economic, Social and Cultural Rights to States parties to the International Covenant on Economic, Social and Cultural Rights, available from http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCESCR%2fUS%2f6395&Lang=en.

to put in place and implement laws and policies prohibiting conduct by family members and third parties, service providers, landowners or providers of general services which undermines the full enjoyment of the right to be included and live independently within the community.

51. States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization. Furthermore, States parties must ensure that private institutions are not established under the guise of “community living”.

52. Support should always be based on individual requirements, not on the interests of the service provider. States parties should establish mechanisms for monitoring service providers, adopt measures which protect persons with disabilities from being hidden in the family or isolated in institutions and children from being abandoned or institutionalized on the grounds of disability, and establish appropriate mechanisms to detect situations of violence against persons with disabilities by third parties. States parties should also prohibit directors and/or managers of residential institutions from becoming guardians of residents.

53. The duty to protect also includes the prohibition of discriminatory practices such as the exclusion of individuals or groups from the provision of certain services. States parties should prohibit and prevent third parties from imposing practical or procedural barriers to living independently and being included in the community, for example by ensuring that services provided are in line with living independently in the community and that persons with disabilities are not denied the possibility to rent or are not disadvantaged in the housing market. General community services open to the public such as libraries, swimming pools, public parks/spaces, shops, post offices and cinemas must be accessible and responsive to the requirements of persons with disabilities, as enshrined in the Committee’s general comment No. 2 (2014) on accessibility.

C. Obligation to fulfil

54. The obligation to fulfil requires States to promote, facilitate and provide appropriate legislative, administrative, budgetary, judicial, programmatic, promotional and other measures to ensure the full realization of the right to live independently and be included in the community as enshrined in the Convention. The obligation to fulfil also requires States parties to take measures to eradicate practical barriers to the full realization of the right to live independently and be included in the community, such as inaccessible housing, limited access to disability support services, inaccessible facilities, goods and services in the community and prejudices against persons with disabilities.

55. States parties should empower family members to support the family members with disabilities to realize their right to live independently and be included in the community.

56. While implementing legislation, policies and programmes, States parties must closely consult and actively involve a diverse range of persons with disabilities through their representative organizations in all aspects concerning living independently in the community, in particular, when developing support services and investing resources in support services within the community.

57. States parties must adopt a strategy and a concrete plan of action for deinstitutionalization. It should include the duty to implement structural reforms, to improve accessibility for persons with disabilities within the community and to raise awareness among all persons in society about inclusion of persons with disabilities within the community.

58. Deinstitutionalization also requires a systemic transformation, which includes the closure of institutions and the elimination of institutionalizing regulations as part of a comprehensive strategy, along with the establishment of a range of individualized support services, including individualized plans for transition with budgets and time frames as well as inclusive support services. Therefore, a coordinated, cross-government approach which ensures reforms, budgets and appropriate changes of attitude at all levels and sectors of government, including local authorities, is required.

59. Programmes and entitlements to support living independently in the community must cover disability-related costs. Furthermore, ensuring the availability of a sufficient number of accessible and affordable housing units is crucial for deinstitutionalization, including housing for families. It is also important that access to housing not be made conditional upon requirements that reduce the autonomy and independence of persons with disabilities. Buildings and spaces open to the public and all forms of transport must be designed in a way that accommodates the requirements of all persons with disabilities. States parties must take deliberate and immediate steps to reallocate funding towards realizing the right of persons with disabilities to living independently in the community.

60. Disability support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities and be sensitive to different living conditions, such as individual or family income, and individual circumstances, such as sex, age, national or ethnic origin and linguistic, religious, sexual and/or gender identity. The human rights model of disability does not allow the exclusion of persons with disabilities for any reason, including the kind and amount of support services required. Support services, including personal assistance, should not be shared with others unless it is based on a decision based on free and informed consent.

61. States parties shall incorporate the following elements into the eligibility criteria for access to assistance: the assessment should be based on a human rights approach to disability; focus on the requirements of the person that exist because of barriers within society rather than the impairment; take into account, and follow, a person's will and preferences; and ensure the full involvement of persons with disabilities in the decision-making process.

62. Cash transfers such as disability allowances represent one of the forms in which States parties provide support for persons with disabilities in line with articles 19 and 28 of the Convention. Such cash transfers often acknowledge disability-related expenses and facilitate the full inclusion of persons with disabilities in the community. Cash transfers also tackle situations of poverty and extreme poverty that persons with disabilities may face. States parties must not add to the hardship faced by persons with disabilities by reducing their income in times of economic or financial crisis or through austerity measures that are inconsistent with human rights standards set out in paragraph 38 above.

63. Support for persons with disabilities should be assessed using a personalized approach and tailored to the specific activities and actual barriers to inclusion in the community that persons with disabilities face. The assessment should acknowledge that persons with disabilities require access to participate in activities that varies over time. States parties should ensure that personalization of support, including cash transfers/personal budgets, take into account and address the challenges that persons with disabilities face when living in rural and/or urban areas.

64. States parties should provide and disseminate timely, up-to-date and accurate information essential for informed decision-making on choices of independent living and support services in the community. This should be in accessible formats, including Braille, sign language, tactile and Easy Read formats and alternative and augmentative modes of communication.

65. States should ensure that personnel working or about to work in disability-related services, including service personnel, decision makers and civil servants monitoring services for persons with disabilities, are adequately trained on independent living within the community, in theory and practice. States should also establish criteria, in line with article 19, concerning entities applying for permission to deliver social support for persons with disabilities to live in the community and assess how they perform their duties. States parties should also ensure that international cooperation in accordance with article 32 of the Convention and the investments and projects undertaken thereby do not contribute to the perpetuation of barriers to independent living within the community but rather eradicate barriers and support the implementation of the right to live independently and be included in the community. After situations of disaster, it is important not to rebuild barriers, as an element of implementing article 11 of the Convention.

66. States parties must ensure access to justice and provide legal aid and appropriate legal advice, remedies and support, including through reasonable and procedural accommodation, for persons with disabilities who seek to enforce their right to living independently in the community.

67. States parties should provide adequate support services to family carers so they can in turn support their child or relative to live independently in the community. This support should include respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers, who often live in situations of extreme poverty without the possibility of accessing the labour market. States parties should also provide social support to families and foster the development of counselling services, circles of support and other adequate support options.

68. States parties must regularly conduct surveys and other forms of analysis providing data on the physical, communication, environmental, infrastructural and attitudinal barriers experienced by persons with disabilities and the requirements for implementing living independently in the community.

IV. Relationship with other provisions of the Convention

69. The right to live independently and be included in the community is interrelated with the enjoyment of other human rights provided for in the Convention. At the same time, it is more than the sum of those rights as it affirms that all rights should be exercised and enjoyed in the community where a person chooses to live and in which alone the free and full development of one's personality can be fulfilled.

70. Consultations with and the active involvement of persons with disabilities, through their representative organizations (art. 4 (3)), is critical for the adoption of all plans and strategies as well as for follow-up and monitoring when implementing the right to independent living in the community. Decision makers at all levels must actively involve and consult the full range of persons with disabilities including organizations of women with disabilities, older persons with disabilities, children with disabilities, persons with psychosocial disabilities and persons with intellectual disabilities.

71. Non-discrimination (art. 5), in terms of living independently and being included in the community, is important in regard to accessing and receiving support services. States parties should define eligibility criteria and procedures for accessing support services in a non-discriminatory way, objectively and focused on the requirements of the person rather than on the impairment, following a human rights-compliant approach. The establishment of specific services for persons with disabilities in the particular circumstances of the persons with disabilities and in accordance with their requirements, such as services for children, students, employees and older persons with disabilities, should not be considered as a discriminatory violation of the Convention, but rather as a just and legally available affirmative action. Persons with disabilities who face discrimination in relation to article 19 must have effective and affordable legal remedies at their disposal.

72. Often, women and girls with disabilities (art. 6) are more excluded and isolated, and face more restrictions regarding their place of residence as well as their living arrangements owing to paternalistic stereotyping and patriarchal social patterns that discriminate against women in society. Women and girls with disabilities also experience gender-based, multiple and intersectional discrimination, greater risk of institutionalization and violence, including sexual violence, abuse and harassment.⁸ States parties must provide affordable, or free, legal remedy and support services for victims of violence and abuse. Women with disabilities who face domestic violence are frequently more economically, physically or emotionally dependent on their abusers, who often act as caregivers, a situation that prevents women with disabilities from leaving abusive relationships and leads to further social isolation. Therefore, when implementing the right to live independently and be

⁸ See Committee on the Rights of Persons with Disabilities, general comment No. 3 (2016) on women and girls with disabilities.

included in the community, particular attention should be paid to gender equality, the elimination of gender-based discrimination and patriarchal social patterns.

73. Cultural norms and values may adversely restrict the choices and control of women and girls with disabilities over their living arrangements, limit their autonomy, oblige them to live in particular living arrangements, require them to suppress their own requirements and instead serve those of others and take certain roles within the family.⁹ States parties should take measures to tackle discrimination and barriers against women in accessing social services and support, as well as ensure that various policies, programmes and strategies concerning access to social services and support take due consideration of the equality between women and men.

74. States parties should also ensure that measures aimed at development, empowerment and advancement of women and girls with disabilities (art. 6 (2)) address gender-based inequalities in accessing support and social protection. States parties should adopt adequate measures to encourage work-life balance (resources, time, services) that support women with disabilities in (re-)entering the open labour market and ensure equal rights and responsibilities between women and men for the exercise of parental responsibilities.¹⁰ It is also the responsibility of States parties to ensure that shelters for victims of gender-based violence are fully accessible to women and girls with disabilities.

75. The existence of adequate and age-sensitive support services for girls and boys with disabilities is of vital importance for the equal enjoyment of their human rights (art. 7). Respecting the evolving capacities of children with disabilities and supporting them in having a say in choices that have an impact on them is critical. 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 with disabilities.

76. When it comes to social interactions and relationships with peers, teenagers may prefer personal assistance or professional sign language interpreters to informal support provided by relatives. States parties should establish innovative forms of support and accessible services for children and adolescents with disabilities through personal contact or through their organizations. Children with disabilities may require support to practise sports or activities in the community with other children their age. Adolescents with disabilities should be enabled to spend time and take part in leisure activities with their peers. States parties must provide assistive devices and technologies that can facilitate the inclusion of adolescents with disabilities in their peer networks. Further, services that facilitate the transition of young people to adulthood, including support with moving out of the family home, starting employment and continuing into higher education, are crucial in supporting independent living.

77. Awareness-raising (art. 8) is essential to create open, enabling and inclusive communities, as article 19 is ultimately about transforming communities. Stereotypes, ableism and misconceptions that prevent persons with disabilities from living independently must be eradicated and a positive image of them and their contributions to society must be promoted. Awareness-raising should be provided for authorities, civil servants, professionals, the media, the general public and persons with disabilities and their families. All awareness-raising activities should be carried out in close cooperation with persons with disabilities through their representative organizations.

78. The rights provided for in article 19 are tied to the obligations of the States parties relating to accessibility (art. 9) because the general accessibility of the whole built environment, transport, information, and communication and related facilities and services open to the public in a community is a precondition for living independently in the community. Article 9 requires the identification and elimination of barriers in buildings open to the public, such as the revision of building and urban planning codes, the inclusion

⁹ *Ibid.*, paras. 8, 18, 29 and 55.

¹⁰ See Committee on the Elimination of Discrimination against Women, general recommendation No. 21 (1994) on equality in marriage and family relations.

of standards of universal design in a variety of sectors and the establishment of accessibility standards for housing.

79. States parties must take into account in advance the obligation to provide support services to persons with disabilities in all disaster risk management activities (art. 11) and make sure that they are not left behind or forgotten. It is also important that barriers are not rebuilt after situations of armed conflict, humanitarian emergencies or the occurrence of a natural disaster. Reconstruction processes must ensure full accessibility for the independent life in the community of persons with disabilities.

80. Equal recognition before the law (art. 12) ensures that all persons with disabilities have the right to exercise their full legal capacity and therefore have the equal right to exercise choice and control over their own lives by choosing where, with whom and how they want to live and to receive support in accordance with their will and preferences. To fully realize the transition to supported decision-making and implement the rights enshrined in article 12, it is imperative that persons with disabilities have the opportunity to develop and express their wishes 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. Furthermore, support in the exercise of legal capacity should be provided using a community-based approach which respects the wishes and preferences of individuals with disabilities.

81. Access to justice as enshrined in article 13 is fundamental to ensure full enjoyment of the right to live independently in the community. 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 living independently in the community can be appealed. Support to enable living independently in the community shall be enforceable as a right and an entitlement. To ensure equal and effective access to justice, substantial rights to legal aid, support and procedural and age-appropriate accommodations are essential.

82. Involuntary institutionalization on the grounds of impairment or associated circumstances such as presumed “dangerousness” or other factors as elaborated by the Committee in its guidelines on article 14 is often caused or increased by a lack of disability-specific support services. Implementing article 19 thus will ultimately prevent violation of article 14.

83. It is of paramount significance to ensure that support services leave no space for potential abuse or exploitation of persons with disabilities or any violence against them (art. 16). Disability-, gender- and age-sensitive monitoring, legal remedies and relief must be available for all persons with disabilities who use services prescribed in article 19 and who may face abuse, violence and exploitation. Since institutions tend to isolate those who reside within them from the rest of the community, institutionalized women and girls with disabilities are further susceptible to gender-based violence, including forced sterilization, sexual and physical abuse, emotional abuse and further isolation. They also face increased barriers to reporting such violence. It is imperative that States include these issues in their monitoring of institutions and ensure access to redress for women with disabilities who are exposed to gender-based violence in institutions.

84. Without support for personal mobility (art. 20), barriers to living independently in the community continue to exist for many persons with disabilities. The provision of affordable and available quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, as enshrined in article 20, is a precondition for the full inclusion and participation of persons with disabilities in their respective communities.

85. Persons with disabilities have the right to access all public information in accessible formats and to seek, receive and express information and ideas on an equal basis with others (art. 21). Communication can be provided in forms and formats of their choice, including Braille, sign language, tactile and Easy Read formats and alternative modes, means and formats of communication. It is important that communication and information flow in both directions and that services and facilities are accessible for individuals who use different ways of communicating. It is of particular importance that information about support services and social protection schemes, including disability-related mechanisms, is

accessible and available from a diversity of sources in order to enable persons with disabilities to make fully informed decisions and choices about where, with whom and how to live and what kind of service is best suited to them. It is also of critical importance that mechanisms to provide feedback and complaints are communication accessible.

86. States parties should ensure that in the provision of support services under article 19, the privacy, family, home, correspondence and honour of persons with disabilities are protected from any unlawful interference (art. 22). In any case of unlawful interference, disability-, gender- and age-sensitive monitoring, legal remedies and relief must be available for all persons with disabilities using support services.

87. The right to living independently in the community is intimately linked with the right to family for children and parents with disabilities (art. 23). The absence of community-based support and services may create financial pressures and constraints for the family of persons with disabilities; the rights enshrined in article 23 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 because of the latter's disability. States parties should provide information, guidance and support to families in upholding their children's rights and promote inclusion and participation in the community.

88. Living independently and being included in the community is inherently linked to inclusive education (art. 24) and requires recognition of the right of persons with disabilities to live independently and enjoy inclusion and participation in the community.¹¹ Inclusion of persons with disabilities in the mainstream education system generates further inclusion of persons with disabilities in the community. Deinstitutionalization also entails the introduction of inclusive education. States parties should note the role that exercising the right to inclusive education will play in building the strengths, skills and competencies necessary for all persons with disabilities to enjoy, benefit from and contribute to their communities.

89. General health facilities and services (art. 25) must be available, accessible, adaptable and acceptable for persons with disabilities in their communities, including the support required by some persons with disabilities (for example those with complex communication requirements, psychosocial disabilities or intellectual disabilities and/or deaf persons) during hospitalizations, surgeries and medical consultations. The provision of nurses, physiotherapists, psychiatrists or psychologists, in hospitals as well as at home, is a part of health care and should not be seen as the fulfilment of a States party's obligation under article 19, but rather under article 25.

90. Independent living in the community, habilitation and rehabilitation (art. 26) are interdependent. For some persons with disabilities, participation in 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 fully and effectively participate in the community. The habilitation and rehabilitation of a person with disability must always take place with his/her free and informed consent. Habilitation and rehabilitation are predominantly relevant in relation to education, employment, health and social matters.

91. The existence of individualized support services, including personal assistance, often is a precondition for effective enjoyment of the right to work and employment (art. 27). Furthermore, persons with disabilities should also become employers, managers or trainers in disability-specific support services. Implementing article 19 will thus help to phase out sheltered employment.

92. To ensure that persons with disabilities enjoy an adequate standard of living (art. 28), States parties should provide, inter alia, access to support services that enable them to live independently. Therefore, there is an obligation on the part of States parties to ensure access to appropriate and affordable services, devices and other assistance for impairment-

¹¹ Committee on the Rights of Persons with Disabilities, general comment No. 4 (2016) on the right to inclusive education.

related requirements, especially for those persons with disabilities who live in poverty. Furthermore, access to public and subsidized housing programmes in the community is required. It is considered contrary to the Convention for persons with disabilities to pay for disability-related expenses by themselves.

93. In order to influence and take part in decisions impacting the development of their community, all persons with disabilities should enjoy and exercise their rights to participation in political and public life (art. 29) personally or through their organizations. Appropriate support can provide valuable assistance to persons with disabilities in exercising their right to vote, to take part in political life and to conduct public affairs. It is important to ensure that assistants or other support staff do not restrict or abuse the choices that persons with disabilities make in exercising their voting rights.

94. Cultural life, recreation, leisure and sport (art. 30) are important dimensions of life in the community in which inclusion can be pursued and achieved, for example by ensuring that events, activities and facilities are accessible to persons with disabilities and are inclusive. Personal assistants, guides, readers and professional sign language and tactile interpreters, among others, contribute to an inclusive life in the community in accordance with the will and preferences of persons with disabilities. It is important that the use of support of any kind is considered part of disability-related expenses as such support services help foster inclusion in the community and independent living. Assistants necessary for participating in cultural and leisure activities should not be required to pay entrance fees. There should also be no restrictions on when, where and for what kinds of activities assistance can be used, nationally and internationally.

95. Data and information must be disaggregated systematically (art. 31) by disability across all sectors, including with respect to housing, living arrangements and social protection schemes as well as access to independent living and support and services. The information should allow for regular analyses of how deinstitutionalization and transition to support services in the community have progressed. It is important that indicators reflect the particular circumstances in every State party.

96. International cooperation (art. 32) must be conducted in a way which ensures that foreign aid is invested in support services in local communities that respect the will and preferences of persons with disabilities and foster their right to choose where, with whom and under what living arrangements they will live, in line with article 19. Investing money obtained within the framework of international cooperation in development of new institutions or places of confinement or institutional models of care is not acceptable, as it leads to the segregation and isolation of persons with disabilities.

V. Implementation at the national level

97. The Committee notes that States parties may face challenges at the national level when implementing the right to living independently and being included in the community. However, in line with the normative content and obligations outlined above, States parties should take the following steps to ensure the full implementation of article 19 of the Convention:

(a) Repeal all laws that prevent any person with disabilities, regardless of the type of impairment, to choose where and with whom and how to live, including the right not to be confined on the basis of any kind of disability;

(b) Enact and enforce laws, standards and other measures with the purpose of making local communities and the environment, as well as information and communication, accessible to all persons with disabilities;

(c) Ensure that social protection programmes meet the requirements of the diverse range of persons with disabilities on an equal basis with others;

(d) Insert the principle of universal design for both physical and virtual space in policies, law, standards and other measures, including monitoring the realization/implementation of obligations; review building codes to ensure that they comply

with the principles of universal design and legislative guidelines on construction, as outlined in the Committee's general comment No. 2;

(e) Provide all persons with disabilities with substantive and procedural rights to live independently within the community;

(f) Inform persons with disabilities about their right to live independently and be included in the community in ways they can understand and provide empowerment trainings with the aim of supporting persons with disabilities to learn how to enforce their rights;

(g) Adopt clear and targeted strategies for deinstitutionalization, with specific time frames and adequate budgets, in order to eliminate all forms of isolation, segregation and institutionalization of persons with disabilities; special attention should be paid to persons with psychosocial and/or intellectual disabilities and children with disabilities currently in institutions;

(h) Create awareness programmes that tackle negative attitudes and stereotypes about persons with disabilities and secure community transformation in an effort to develop individualized and accessible mainstream services;

(i) Ensure the participation of persons with disabilities, personally and through their representative organizations, in transforming support services and communities and in the design and implementation of deinstitutionalization strategies;

(j) Design comprehensive policies and legislative guidelines and allocate financial resources for the construction of affordable and accessible housing units, the built environment, 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;

(k) Allocate resources to the development of appropriate and sufficient person-directed/"user"-led and self-managed support services for all persons with disabilities, such as personal assistance, guides, readers and professionally trained sign language or other interpreters;

(l) Design tendering processes for providing support services for persons with disabilities living independently in the community that take into account the normative content of article 19;

(m) Establish mechanisms to monitor existing institutions and residential services, deinstitutionalization strategies and the implementation of living independently within the community, bearing in mind the role of the independent monitoring frameworks;

(n) Carry out the monitoring and implementation envisaged under article 19 in full consultation with and with the participation of persons with disabilities, through their representative organizations.
