

## Committee on the Rights of Persons with Disabilities

### Draft General Comment No. 5 (2017)

#### Article 19: Living independently and being included in the community

### **I. Introduction**

1. Throughout history, persons with disabilities have been denied choice and control across all areas of their lives. Until today, they have often been presumed to be unable to live independently among others. Support is unavailable or tied to particular living arrangements and community infrastructure is inaccessible. This has led to abandonment, dependence on family members, institutionalization, isolation and segregation of persons with disabilities.

2. As an answer to human rights violations against persons with disabilities, article 19 of the Convention on the Rights of Persons with Disabilities recognises the equal right of all persons with disabilities to live independently and be included in the community, with choices equal to others. The foundation of this right 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 regarded as subjects of rights. 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 understand and apply article 19. These are: non-discrimination (art. 3 (b)), respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)), equality of opportunity (art. 3 (e)), accessibility (art. 3 (f)), equality between men and women (art. 3 (g)) and respect for the evolving capacities of children with disabilities to preserve their identity (art. 3 (h)).

4. Independent living and an inclusive life in the community are ideas that are inextricably linked with the disability rights movement. Persons with disabilities have claimed the right to participate in all areas of community life and sought control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities and services are made fully available to them on an equal basis with others.

5. In the Preamble to the Convention, States parties recognized that the majority of persons with disabilities live in conditions of poverty and stressed the need to address the negative impact of poverty. The cost of social exclusion is high and strategies to tackle poverty often require significant extra budgetary resources. However, policies for achieving social inclusion of persons with disabilities, including through the promotion of their right to independent living, represent a cost-effective mechanism to ensure sustainable development and eradicate poverty.

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

plays a distinct role as one of the widest ranging and most intersectional articles of the Convention and has to be considered as a precondition for the implementation of the Convention across all articles.

7. Article 19 entails civil and political as well as social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to independent living and being included in the community can only be realized if all civil, social and cultural rights enshrined in this norm are fulfilled. Modern human rights theory recognizes that in order to be realized, all human rights require resources. Systematic realization also requires structural changes which have to be taken step by step, no matter whether civil and political or social, economic and cultural rights are at stake.

8. Article 19 reflects the diversity of cultural approaches to human living and ensures that the right covered under the article is not biased towards certain cultural norms and values. Living independently and being included in the community are concepts of human living across the globe, applied to the context of disability. They mean exercising freedom of choice and control over decisions affecting one's life with the same level of self-determination and interdependence within society as everybody else. The realization of the right therefore must be effective in different economic, social, cultural and political contexts. The Committee also finds it important to reaffirm that the right to live independently and be included in the community refers to all persons with disabilities, irrespective of support required, age, impairment, sex, race, ethnicity, migration status, income or any other relevant category.

9. The right to live independently and be included in the community is deeply rooted within the normative framework of international human rights. 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 (art. 12 ICCPR) and the right to an adequate standard of living, including adequate clothing, food and housing (art. 11 ICESCR) both form the basis for the right to live independently and be included in the community. Both the liberty of movement as well as the right to an adequate standard of living, form indispensable conditions for human dignity and the free development of a person.<sup>1</sup>

10. The Convention on the Elimination of Discrimination against Women (CEDAW) emphasizes the equality of women and men and condemns discrimination against women in all its forms (art.1). CEDAW 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 of the Convention on the Rights of the Child enshrines the right of children not to be separated from their parents unless it is necessary for the best interest of the child. Article 23 (1) further specifies that all children with disabilities should enjoy a life in dignity with conditions that promote self-reliance and facilitates active participation in the community. In its

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<sup>1</sup> Human Rights Committee, General Comment No. 27, para. 1; Committee on Economic, Social and Cultural Rights, General Comment No. 4, para. 7.

General Comment No. 9, the Committee on the Rights of the Child also expresses its concern at the high number of children with disabilities placed in institutions and urges States parties to set up de-institutionalization programs for children with disabilities.

12. In order for everyone to enjoy the right, the principle of non-discrimination is essential. Equality and non-discrimination are fundamental concepts of international human rights law and enshrined in all core human rights instruments. In its General Comment No. 5, 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 ICESCR 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 which fully respect the human rights of persons with disabilities.<sup>2</sup>

13. Article 19 and the content of this General Comment must also be understood in the light of The New Urban Agenda (Habitat III) and as an integral part of 2030 Development Agenda and Sustainable Development Goals (SDGs). The New Urban Agenda advocates a vision of cities and human settlements where all persons are able to enjoy equal rights and opportunities by promoting inclusive, just, safe, healthy, accessible, affordable, resilient and sustainable cities and human settlements. The SDGs, referencing the principles of accessibility and universal design, contain 13 goals and 7 targets which make specific references to persons with disabilities. In connection with article 19 of the Convention, target 10.2, empowerment and promotion of social, economic, 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.

14. The Committee on the Rights of Persons with Disabilities has noted significant advancements in the past decade concerning the implementation of article 19. However, the Committee continues to observe a clear 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 concerning decisions about the living arrangements of persons with disabilities (interrelation with article 12);
- b. Inadequacy of social support and protection schemes for ensuring independent and community living (interrelation with article 28);
- 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 (interrelation with article 14);
- e. Lack of deinstitutionalization strategies and plans;
- f. Negative attitudes, stigma and stereotypes that prevent persons with disabilities from being included in the community and accessing available support;
- g. Misconceptions about independent living and culture;
- h. Lack of available, acceptable, affordable, adaptable and accessible services and facilities within the community, such as transport, health care, schools, public parks/spaces, housing, theatres, cinemas, shops and public buildings;

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Committee on Economic, Social and Cultural Rights, General Comment No. 5, para. 15.

- 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; and
- k. Decentralization, resulting in disparities between local authorities and unequal chances of independent and community living in a State party (inappropriate implementation of article 4 (5)).

## II. Normative content of article 19

### A. Definitions

15. In order to realise appropriate implementation, the Committee is aware of the need to define the fundamental concepts of the right to live independently and be included in the community, including the following:

(a) **Independent Living**, which means that individuals with disabilities are enabled to exercise control over their lives and make all decisions that concern their lives. This includes, but is not limited to: place of residence, daily routine, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual and reproductive rights. All these activities are linked to the development of a person's identity and personality: where we live, 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. These actions and decisions constitute what we are. Thus, the concept of independent living is an essential part of the individual's autonomy and freedom. Living independently does not necessarily mean living alone; it should also not be interpreted as the ability of carrying out daily activities by oneself. Rather, it should be regarded as the freedom to choice and control, as enshrined in article 3 (a) of the Convention. Independence as a form of autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities.

(b) **Community living**: The right to be included in the community relates to the principle of full and effective inclusion and participation in society as enshrined in article 3 (c) of the Convention. It means being social and having access to all services offered by the community to its members and to specialized services offered to persons with disabilities to enable them to be fully included and to participate in social life. These services can relate to housing, personal care, transportation, shopping, cinemas and all other facilities and services offered to the public. The right to be included in the community also means having access to all measures and events of political and cultural life in the community. These can be elections as well as public meetings of local governments, sports events as well as theatre festivals. Although community may primarily be understood as geographic or physical location, it should not be limited to such an understanding. Community is to be understood as every place of social interaction and communicative relations, and not just as a specific geographic or physical location. Hence, persons with disabilities must be entitled to be independent in community everywhere, and for all type of activities.

(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 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 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.<sup>3</sup> 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.

(d) **Personal assistance** refers to person-directed/user-led human support delivered to a person with disability. Personal assistance is a tool for independent living. Although definitions of personal assistance may vary, there are certain elements which distinguish it from other types of support. 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 a person/user's life circumstances. 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. Persons with disabilities have the option to custom-design his or her own service, i.e. decide by whom, how, when, where and in what way the service is delivered. Persons with disabilities who require personal assistance can freely choose their preferred degree of personal control over service delivery according to their requirements, capabilities, life circumstances and preferences. Even if the responsibilities of the employer are contracted out, the person with disability always remains at the center of decision-making processes concerning the assistance. The control of the personal assistance can be through supported decision-making.

16. Independent and community living as well as personal assistance have become popular terms that nowadays are frequently used by organizations providing residential or institutional support services. Person-directed/User-led disability organizations have pointed out the counteractive effect of such practices that mislead assumptions by the public. Residential services, where housing and support are delivered in one package, cannot be counted as personal assistance. Independent and community living can also not be counted as personal assistance if the assistance is only provided within certain arrangements, such as a group home. Institutionalized settings are not compliant with the concepts of independent and community living.

## **B. Article 19, chapeau**

17. Article 19 of the Convention 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 and be included in the community to be realized, state parties have to 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.

18. 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 or community living.

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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.

Whereas the right to independent living refers to an individual dimension, i.e., the place of residence, lifestyle and most importantly, the living arrangements of a person, the right to community living entails a social dimension, i.e., social interactions with others in the community. The right as enshrined in article 19 covers both concepts.

19. Article 19 explicitly refers to all persons with disabilities; thus neither legal capacity issues nor the level of support required may be invoked in order to deny the right to independent and community living to persons with disabilities.

20. In some State parties, individuals with high demands in personal assistance are sent to institutions if the expected calculated costs for independent and community living exceed a predefined level/amount of institutional costs. Another situation identified by the Committee is the presumption that persons with high support requirements are unable to live independently and be included in the community. Particularly, persons with intellectual impairments, are often assessed as being unable to live outside of institutionalized settings. Such reasoning opposes article 19 of the Convention 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 requirement.

21. Different cultures can also challenge the concept of Independent living in accordance with the Convention. When young persons with disabilities are living in institutional settings with elderly persons they may face the risk of living in an environment where the culture of support and services may be determined by the age of the majority, hence not allowing young persons with disabilities to develop an identity and live their life in an age-appropriate mode -as 'young'.

22. All persons with disabilities, including the young, should be free to choose being part of the culture they wish. Article 19 takes into account cultural differences and requires that persons with disabilities have the same choices that other people have in their communities, in all areas of life.

23. The paradigm shift from the medical model to the human rights model of disability, which lies at the heart of the Convention, prohibits discrimination and deprivation of human rights based on impairment. Persons with disabilities of all ages fall within the personal scope of the article. Children with disabilities, adults and older persons with disabilities are right-holders under article 19. Women and men with disabilities enjoy equal protection under the scope of article 19. Furthermore, the right to living independently and being included in the community encompasses protection of persons with disabilities belonging to ethnic groups, linguistic and/or religious minorities. Article 19 should also be ensured irrespective of migrant, asylum-seeking and refugee status. Migrants with disabilities and/or their children who live with disabilities should have equal access to social protection and support.

### **C. Article 19 (a)**

24. To choose one's place of residence and to 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: daily schedule and routine as well as way of life and lifestyle of a person, covering private and public spheres in a daily and long term dimension.

25. 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 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. Furthermore, they might not be allowed to exercise legal capacity due to legal restrictions deriving from guardianship laws or similar legal norms or decisions which do not allow persons with disabilities to exercise legal capacity. Even if no formal laws are in place, others, like families or caregivers, sometimes exercise control and restrict an individual's choices by acting as substitute decision-makers.

26. Legal capacity and equal recognition before the law are the basis of the realization of independent and community living for adults with disabilities. Article 19 is therefore linked to the recognition and exercise of legal capacity as enshrined in article 12 of the Convention and further explained in General Comment No. 1 Legal Capacity (2014) to the Convention. The recognition of choices and decisions of an individual is a precondition for living independently and being included in the community. At the same time, decisions, will and preferences and the exercise of legal capacity, are always bound to social interactions, to others within the respective community where one lives and can freely pursue one's personal development and fulfilment.

#### **D. Article 19 (b)**

27. Article 19 (b) has to be interpreted in line with the human rights model of disability. Hence, individualised support services must be considered a right instead of a form of medical care or charity. For many persons with disabilities, access to a range of individualised support services is a precondition for independent and community living. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences.

28. Literal (b) specifies various individualised services which fall within this category of support services. In-home services are services which are delivered to the home of the person. Residential services are services which offer persons with disabilities support as well as a place to live. They can be useful when persons with disabilities make the transition from institutions to independent and community living and might be necessary for persons who have lived in institutional settings for a long time and need to find out how they prefer to live. Other community support services include personal assistance services or similar person-directed/user-led support.

29. Individualised services encompass a whole range of personalized services, some of which have been exemplified under article 19 (b). In addition to personal assistance, these services might include personal readers or sign language interpreters, guide dogs/ service dogs, social work services, but also technical aids such as ICT software and equipment, wheelchairs, dressing aids, guide canes and similar equipment. 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.

30. The text does not specify other services. While community support services may vary in name, type or kind according to the cultural, economic and geographic specifics of the State party, all services must be designed "to support living and inclusion in the community and to

prevent isolation or segregation from the community”. They may be named respite services, supported parenting or parent’s night out services in one country and individual or group counselling services or community work services in another. It is important that the purpose of these services is the realization of full independent and community living. Therefore, any institutional form of support is not covered by article 19 (b).

31. It is also relevant to keep in mind that both individualised and general services have to be designed and delivered in a mode which supports the overall purpose of the norm: full and effective inclusion and participation.

### **E. Article 19 (c)**

32. Services and facilities mentioned in this section of the article are non-disability specific community services and facilities, which persons in the community who do not have disabilities use. They cover a wide range of services, such as public libraries, hospitals, schools, transport, shops, markets, museums and similar facilities and services. These must be accessible on an equal basis with others, available, affordable and acceptable for all persons with disabilities as well as adaptable and responsive to the requirements of persons with disabilities in a given community.

33. Accessibility of community facilities, goods and services, as well as inclusive education and health are a sine-qua-non for inclusion and participation of persons with disabilities in the community. Various de-institutionalization programs have shown that the closure of residential institutions, regardless of their size and the relocation of inhabitants in the community or with their families, in itself is not enough. Unless such reforms are accompanied by comprehensive service and community development programs, including awareness programs, they largely fail.

34. Adaptability means that accessibility planning and implementation needs to be responsive to the requirements of persons with disabilities in general and particularly responsive to specific groups of persons with disabilities living in a given community. For example, in one community, a larger share of the population may be deaf-blind whereas in another, there might be a high percentage of children and students with disabilities or older persons with disabilities. These groups may face different accessibility barriers which need to be addressed. Therefore, effective data collection disaggregated by age, sex, ethnic background, social condition, refugee, asylum-seeking, migrant situation and analysis are of paramount importance.

35. In terms of material scope, article 19 covers access to housing, individual services and community facilities and services. 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 have to live in the same building, complex or neighborhood. 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 to provide the right and possibility for persons with disabilities to choose from. In addition, housing must be affordable to persons with disabilities, which often means individually subsidised, as persons with disabilities tend to have less income compared to others.



36. Community services also must be available, i.e., 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 that persons with disabilities often have low income. They also need to be acceptable which means that they must be of the same quality as services provided to the general public and be gender, age and culturally sensitive.

37. It is important to mention that there is a logical link between the requirement for individualized support and the accessibility of community services and facilities. The more the latter are accessible to persons with disabilities living in the community, the less individualized services and support will be required by the individual.

38. Neither are packages of individualised services which do not allow choice and control, nor are segregated community services such as special schools, special shops or special transportation, effective measures to prevent isolation or segregation from the community and to fully enable independent and community living. Packages of individualised services, such as combined residential and personal assistance services, are sometimes offered on the premise of cost efficiency. However, while this premise itself can be rebutted economically,<sup>4</sup> aspects of cost efficiency must not override the core of the human right at stake. The possibility to choose is one of the three key elements of the right to live independently and be included in the community.

39. The right to equal community services corresponds with the duty to ensure participation and involvement of persons with disabilities in processes related to community facilities and services in order to ensure that they are responsive to specific requirements and gender and age sensitive, and they must be available to allow for spontaneous participation by people with disabilities within the community.

## **F. Core elements**

40. The Committee finds it important to identify core elements of article 19 in order to ensure that the realization of a minimum essential level of the right to live independently and be included in the community is incumbent upon every State party. States parties should ensure that core elements of article 19 are always respected, particularly in times of financial or economic crisis. These core elements are:

- (a) To have legal capacity to decide where and with whom and how to live is a right for all persons with disabilities, irrespective of impairment;
- (b) The right to choose where to live requires a realistic option of accessible housing to choose from;

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<sup>4</sup> In the long term, inclusive societies, in which persons with disabilities fully participate and contribute to the economic, social, political and cultural life, are more cost effective. Hence, although high quality individualized support and inclusive mainstream services may require initial investments, they are more cost-efficient in the long run (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. 65).

- (c) The right to live independently does not entail dependence on informal support from family and friends;
- (d) To have access to basic personalised and human rights-based disability specific services;
- (e) To have access to basic mainstream community-based services and support on an equal basis with others; and
- (f) The possibility of living independently must not be negatively affected by measures taken to respond to economic constraints.

### **III. Obligations of States parties**

41. States parties obligations have to reflect the hybrid legal character of the norm. As a civil right, article 19 (a), the right to choose one's residence and where, how and with whom to live, is immediately applicable. Article 19 (b), the right to access individualised assessed disability support services, is a classic social right. Article 19 (c), the right to avail community services and facilities, is a social and a cultural right, given that many community services, such as cinemas, public parks, theatres and sports facilities, serve cultural purposes. Social and cultural rights are subject to progressive realization.

42. In order to achieve the realization of social and cultural rights, States parties must take steps to the maximum of their available resources (art. 2 (1) ICESCR). While full realization of the goals may be achieved progressively, steps towards it must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means.<sup>5</sup> The systematic realization of the right to independent and community living requires structural changes. In particular, this applies to de-institutionalization in all its forms. In this regard, States parties have the immediate obligation to enter into strategic planning in close and respectful consultation with representative organizations of persons with disabilities to replace any institutionalized settings with independent living and community-based services that comply with all general principles of article 3 of the Convention. The margin of appreciation of States parties is related to the mode of services but not to the question of replacement.

43. An exemption from progressive realization regarding article 19 (b) and (c) is the "minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights" incumbent upon the States parties.<sup>6</sup> If persons with disabilities are deprived of the core elements of independent and community living as listed in paragraph 40 of this General Comment, this counts as a failure to fulfill States parties' obligations. States parties can only attribute the failure to meet the obligations to a lack of resources if they demonstrate having made every effort to use all resources at their disposal in order to satisfy those minimum obligations as a matter of priority.<sup>7</sup>

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<sup>5</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 3.

<sup>6</sup> Ibid. para. 10.

<sup>7</sup> Ibid.

44. The duty of progressive realization also entails a presumption against retrogressive measures in the enjoyment of economic, social and cultural rights. Retrogressive measures only should be adopted after careful consideration of all alternatives, if they are duly justified by references to the totality of the rights provided for in the Convention, in the context of the use of the maximum available resources of the State party.<sup>8</sup>

45. States parties are prohibited from taking retrogressive measures with respect to the core elements of the right to independent and community living listed in paragraph 40 of this General Comment. While the Committee notes that many States parties face serious financial burdens as a result of the global financial crisis (2008), they should ensure that persons with disabilities are protected against social cutbacks because the effects affects them harder than the general population.<sup>9</sup>

46. The obligation to take measures to overcome discrimination on the basis of disability and to achieve de facto equality of persons with disabilities also is also exempt from progressive realization (art. 4 (1) CRPD). States parties are under immediate obligation to eliminate discrimination against individuals or groups of persons with disabilities and to guarantee their equal right to independent and community living and participation. This requires States parties to repeal or reform laws, policies and practices that prevent persons with disabilities from, for example, choosing their place of residence, from access to housing, from renting accommodation or from accessing general community facilities and services on an equal basis with others. The duty to provide reasonable accommodation (art. 5 (3) CRPD) is also not subjected to progressive realization.

47. The right to decide where, how and with whom to reside also embraces the decision to live in institutional care settings, because there is no obligation to live under a particular living arrangement. However, as article 19 of the Convention is about being included in the community, the right to choose a residential, institutional setting does not correspond with a states' party duty to maintain institutions or to ensure the availability of residential support services.

## **A. Obligation to respect**

48. The obligation to respect requires States parties to refrain from directly or indirectly interfering with the individual exercise of the right to living independently and being included in the community. States parties should not limit or deny anyone access to independent and community living, including through laws which directly or indirectly affect the autonomy and options of persons with disabilities autonomy and options to choose their place of residence or where, how and with whom to live. States parties should reform laws that impede the exercise of the rights enshrined in article 19 of the Convention. Examples include guardianship and mental health laws which force persons with disabilities to live in institutions as well as laws on social protection or building law which prioritize residential or institutional services.

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<sup>8</sup> Committee on the Rights of Persons with Disabilities, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland (CRPD/C/15/R.2/Rev.1), para. 46.

<sup>9</sup> Committee on the Rights of Persons with Disabilities, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland (CRPD/C/15/R.2/Rev.1).

49. The obligation to respect also requires States to repeal and refrain from enacting laws, policies and structures that create barriers in access to disability support services as well as general community facilities and services.

## **B. Obligation to protect**

50. The obligation to protect requires States parties to take measures to prevent third parties from directly or indirectly interfering with the enjoyment of the right to independent and community living. The duty to protect requires States parties to put in place and implement laws and policies prohibiting conduct by third parties, such as families, service-providers, landlords or providers of general community services, which undermines the full enjoyment of the right. If support services are not provided directly by States parties, they have to ensure that they are in line with the rights enshrined in article 19 of the Convention.

51. Support should always be based on the individual requirements, not the interest of the service provider. States parties should establish monitoring mechanisms of service providers, adopt measures which protect persons with disabilities from being hidden in the family or isolated in institutions, protect 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 that directors and/or managers of residential institutions become guardians of the residents.

52. 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, such as ensuring that services provided are in line with independent and community living and that persons with disabilities are not denied the possibility to rent or disadvantaged in the housing market. General community services open to the public such as libraries, swimming pools, public parks/spaces, shops, post offices or cinemas must be accessible and responsive to the requirements of persons with disabilities, as enshrined in General Comment No. 2 Accessibility (2014)<sup>10</sup> to the Convention.

53. States parties should also ensure that autonomy and self-determination of persons with disabilities concerning their living arrangements prevail and are protected in family contexts. Families can contribute to the realization of the right to independent living but their role does not replace States parties obligations in the exercise of the right to living independently and being included in the community. States parties should prevent and combat *de facto* guardianship<sup>11</sup> of persons with disabilities by members of the family, as well as raise awareness and build capacity among families and community networks about the individual autonomy of persons with disabilities, including the freedom to make own choices, and independence concerning place of residence, how and with whom to live.

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<sup>10</sup> [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en)

<sup>11</sup> The Committee has expressed concern about *de facto* guardianship and denial of legal capacity in COBs on See COBs Kenya (CRPD/C/KEN/CO/1 para. 23), Uganda (CRPD/C/UGA/CO/1 para. 22).

## **C. Obligation to fulfill**

54. The obligation to fulfill requires States to adopt appropriate legislative, administrative, budgetary, judicial, 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 fulfill also requires States parties to take measures to eradicate practical barriers to the full realization of the right to independent and community living, such as inaccessible housing, limited access to disability support services, inaccessible facilities and services in the community and prejudices against persons with disabilities.

55. While implementing legislation, policies and programs, States parties must closely consult and actively involve a diverse range of people with disabilities through their representative organizations on all aspects concerning independent and community living, in particular, when it comes to developing support services and investing resources in support services within the community.

56. States parties should adopt a strategy for de-institutionalization. De-institutionalization includes the duty to implement structural reforms. It requires a systemic transformation which goes beyond the closure of institutional settings and requires the establishment of a range of individualized support services as well as inclusive community services. Therefore, a coordinated, cross-government approach which ensures reforms on all levels and sectors of government, including local authorities, is necessary. It is also important that resources are allocated to community support services and that the creation of new institutions or the structural refurbishment of existing institutions is ended. If support services do not exist, it is relevant for States parties not to reproduce outdated models or create institutions, but rather implement approaches which enable persons with disabilities to independent and community living.

57. Programs and entitlements to support living in the community must cover disability-related costs. Furthermore, ensuring the availability of sufficient number of accessible and affordable housing is central for de-institutionalization, including housing for families. It is also important that access to housing is not made conditional upon requirements that reduce autonomy and independence of persons with disabilities. Public buildings and spaces and all forms of transport must be designed in a way to accommodate the requirements of all persons with disabilities.

58. Disability support services must be available, accessible and acceptable to all persons with disabilities and be sensitive to different living and identity circumstances, such as sex, age, religion and sexual identity. A human rights-based approach to support also means that support systems, including personal assistance, do not exclude persons with disabilities because of their impairment or the kind of support they require. This is especially important for persons with intellectual and/or psychosocial impairments or complex support requirements. Furthermore, support should not be limited to a number of pre-established activities, should not be tied to specific living arrangements, must be provided irrespective of persons with disabilities having a family or the income of the individual or family and should be delivered on the grounds of free and informed consent. Independent living is about the right to live independently and not about maintaining the regime of 'Care'.

59. States parties should ensure that eligibility criteria for access to support incorporates the following elements: The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment, take into account a person's will and preferences and ensure the participation of persons with disabilities in the decision-making process. It is important to adopt an open concept of disability compliant with article 1 of the Convention.

60. 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 recognise disability-related expenses and facilitate the 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 should not add to the hardship faced by persons with disabilities, by reducing their income in this period of austerity measures.

61. Cash transfers could be subjected to a conditionality regime and respond to a distribution criteria in the States party. However, States parties should ensure that the conditionality regime is in line with the human rights model of disability. When assessing persons with disabilities the focus should be on the disabilities that hinder their participation in society rather than on impairments. Prioritization on the basis of impairment could adversely affect persons with disabilities who are not being supported to the extent that they require. States parties should ensure that the conditionality regime does not curtail the provision of support and the ability of persons with disabilities to take part in community life.

62. Personalization: Support for persons with disabilities should be tailored to the specific situations and actual barriers that persons with disabilities face in being included in the community. States parties have allocated resources to recognise personal budgets for persons with disabilities with the purpose of facilitating access to community support, including personal assistance. However, the Committee has observed that in some cases, personal budgets do not necessarily allow persons with disabilities to have access and control over community support services. States parties should ensure that persons with disabilities are entitled to access personal budgets irrespective of their age, sex, ethnic background, language, social condition, migrant, asylum-seeking or refugee status. States parties should ensure that personalization of support, including personal budgets, take into account and address the challenges that persons with disabilities face when living in rural and or urban areas.

63. 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 in accessible formats, including braille, sign language, tactile, easy to read formats and alternative and augmentative modes of communication.

64. States should ensure that professionals 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. Training should also be directed at professionals who formerly worked or currently work in residential institutions to ensure that they actively contribute to de-institutionalization and the transformation of support services.

65. Often, the right to living independently and being included in the community is violated not because resources are not available, but because they have been misallocated. Misallocation of resources into institutionalized support services is a clear violation of article 19. States parties must take deliberate and immediate steps to reallocate funding into independent and community living programs and phase out funding for institutional care.

66. States parties should also ensure that international cooperation, investments and projects do not contribute to the perpetuation of barriers to independent and community living but rather eradicate them 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.

67. States parties should ensure access to justice and provide 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.

#### **IV. Relationship with other provisions of the Convention**

68. 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.

69. For the adoption of all plans and strategies as well as for the follow-up and monitoring when implementing the right to independent and community living, decision-makers at all levels must actively involve and consult (art. 4 (3)) a diverse range of persons with disabilities through their representative organizations, including those representing women and children with disabilities. This concerns all aspects of independent and community living, in particular, the development and investment of resources in services, both disability specific and mainstream.

70. Non-discrimination (art. 5) in terms of living independently and being included in the community is important in regards to accessing and receiving support services. Eligibility criteria and procedures for accessing support services need to be defined in a non-discriminatory way, objective and focus on the requirements of the person rather than the impairment, following a human-rights based approach. Setting up specific services for particular groups of persons with disabilities in accordance with their requirements, such as services for children, students or employees with disabilities, is not considered as a discriminatory violation of the Convention but rather as just and legal available affirmative action. Persons with disabilities who are facing discrimination in relation to article 19 must have effective and affordable legal remedies at their disposal.

71. Often, women and girls with disabilities (art. 6) face more restrictions regarding their place of residence as well as their living arrangements due to paternalistic stereotyping against women in society. Women and girls with disabilities often also experience gender-based, multiple and intersectional discrimination, institutionalization, violence and abuse.<sup>12</sup> Therefore, when

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Committee on the Rights of Persons with Disabilities, General Comment No. 3.

implementing the right to live independently and be included in the community, particular attention should be paid to gender equality.

72. 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 and take certain roles within the family. 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. States parties should also ensure that measures aimed at development, empowerment and advancement of women and girls with disabilities (article 6 (2) of the Convention), address gender-based inequalities in accessing support and social protection.

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

74. When it comes to social interactions and relationships with peers, teenagers may prefer personal assistance to informal support provided by relatives. States parties should establish innovative forms of support and accessible services for children and adolescents with disabilities. Children with disabilities may require support to practice sports or activities in the community according to their age. Adolescents with disabilities should be enabled to spend time and take part in leisure activities with their age peers. States parties should provide devices, such as adapted wheelchairs for practicing sports as well as personal assistance that can facilitate the inclusion of adolescents with disabilities in their peer networks.

75. Awareness-raising (art. 8) is essential to create open, enabling and inclusive communities as article 19 ultimately is about transforming communities. Negative stereotypes and misconceptions that prevent persons with disabilities from living independently must be eradicated and their positive image and 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.

76. 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 all public places, transport, information, communication and facilities and services open to the public in a respective community is a precondition for independent and community living. Article 9 requires the identification and elimination of barriers in buildings open to the public, such as the revision of building control acts and urban planning codes, the inclusion of standards of universal design in a variety of sectors, and the establishment of accessibility standards for housing.

77. States parties must take into account the need to provide support services to persons with disabilities in all disaster risk management activities (art. 11) in order to make sure they are



not left behind or forgotten. It is also important that barriers are not rebuilt after natural disasters or armed conflicts.

78. 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 choose and control over their own lives by choosing where, with whom and how they want to live and to receive support according to their will and preferences. To fully realize the transition from substitute 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 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. Furthermore, 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.

79. Placing persons with disabilities in institutions or depriving them of their liberty because of their impairment or against their free will, or also because there is no support available in the community is a violation of article 14.

80. It is of paramount significance to ensure that support services leave no space for potential abuse, 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.

81. Without support of personal mobility (art. 20), barriers to independent and community living remain existent 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 pre-condition for the full inclusion and participation of persons with disabilities in their respective communities.

82. 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 undertaken in forms and formats of their choice, including Braille, sign language, tactile, easy to read formats and alternative modes of communication. It is of particular importance that information about support services and social protection schemes, including disability related mechanisms, is 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.

83. States parties should ensure that in the provision of support services under article 19, the privacy, family, home, correspondence and honor 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 of services.

84. The right to independent and community living is intimately linked with the right to family for children and parents with disabilities (art. 23). If community based support and services are not in place, this may create financial pressures and constraints for the family of persons with

disabilities; 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. States parties should provide information, guidance and support to families in upholding their children's rights and promote inclusion and participation in the community so that families are in a better position to contribute to independent and community living.

85. Independent and community living are inherently linked to inclusive education (art. 24), health care (art. 25), rehabilitation (art. 26) and work and employment (art. 27). Inclusive education (art. 24) requires recognition of the right of persons with disabilities to live independently and enjoy inclusion and participation in the community. Inclusion of persons with disabilities in the mainstream education system generates further inclusion of persons with disabilities in community. De-institutionalization 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.

86. General health facilities and services (art. 25) should be accessible for persons with disabilities in their respective communities on an equal basis with others. It is also important to distinguish support services as envisaged in article 19 of the Convention from health care according to article 25. The provision of nurses and physiotherapists, in hospitals as well as at home, is a part of health care and should not be seen as the fulfilment of a States parties obligation under article 19.

87. There is interdependence between independent and community living and rehabilitation (art. 26). 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 participate in the community. Rehabilitation is dominantly relevant in relation to education, employment, health and social matters.

88. The existence of individualised support and personal assistance often is a pre-condition for effective enjoyment of the right to work and employment (art. 27). Furthermore, persons with disabilities can also become employers, managers or trainers in support services according to article 19. Sheltered work prevents inclusion in and interaction with the community.

89. To ensure that persons with disabilities enjoy an adequate standard of living (art. 28), States parties should provide, inter alia, 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-related requirements, especially for those persons with disabilities who live in poverty. Furthermore, access to public and subsidized housing programs in the community is required. Disability-related costs should be covered by additional resource allocations to avoid persons with disabilities paying for disability-related expenses privately and their standard of living being affected in a discriminatory manner.

90. 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) on an equal basis with others. Adequate 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.

91. Cultural life, recreation, leisure and sports (art. 30) are important dimensions of community life in which inclusion can be pursued and achieved, for example by ensuring that events, activities and facilities are accessible to persons with disabilities and inclusive. Personal assistants, guides, readers, sign language and tactile interpreters, amongst others, contribute to an inclusive life in the community according to the will and preferences of persons with disabilities. It is important that the use of support of any kind is considered as disability-related extra expenses. Assistants should be free of paying entrance. There also should not be restrictions on when, where and for what kind of activities to use the assistance, nationally and internationally.

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

93. All 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 which living arrangements they will live in line with article 19. Investing money obtained in the framework of international cooperation into development of new residential institutions is not acceptable as it leads to segregation and isolation of persons with disabilities.

## **V. Implementation at the national level**

94. 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 persons with disabilities to choose where and with whom and how to live. Enact and enforce laws with the purpose to make local communities and environment as well as information and communication accessible to all persons with disabilities;

(b) Promote the principle of universal design in law and policy, including monitoring the realization/implementation of the obligations;

(c) Provide persons with disabilities with substantive and procedural rights to independent living and community living;

(d) Adopt clear and targeted strategies for de-institutionalization with specific timeframes and adequate budgets in order to eliminate all forms of isolation, segregation or 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;

(e) Create awareness that will counteract negative attitudes and stereotypes about persons with disabilities and secure community transformation in an effort to develop individualized and accessible community services;

(f) Ensuring participation of persons with disabilities, through their representative organizations, is pivotal in transforming support services and communities;

(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 for violations by public or private authorities. Such guidelines should be mandatory and address the issues of accessibility and responsiveness to the requirements of all persons with disabilities. States parties must identify a unit of government that will be responsible for monitoring compliance with such guidelines;

(h) Review their building codes in order to comply with principles of universal design and legislative guidelines on construction as outlined in the Committee's General Comment No. 2 Accessibility (2014);

(i) Invest a sizable percentage of their funds into the development of appropriate and sufficient person-directed/user-led and self-managed support services, such as personal assistance, readers, sign language or tactile interpreters;

(j) Provide or subsidize assistive devices that will enable the full inclusion and independence of persons with disabilities in all spheres of life, including education, employment, health and social affairs in line with SDG 11, targets 11.1, 11.2 and 11.7. This requires that states parties designate a certain percentage of their national budgets to the provision of such services. Accordingly, this requirement should extend to all federating units of a State party in line with article 4 (5) of the Convention;

(k) Put in place appropriate mechanisms to monitor existing institutions and residential services, de-institutionalization policies and the implementation of independent and community living. It is important that States parties develop and apply indicators which take into account the conditions and structures that exist in a given State party. Independent monitoring mechanisms and National Human Rights Institutions operating under the Paris Principles play an important role and should be given sufficient resources. Regardless of the monitoring mechanism put in place, its independence must be secured and it must be guided by the standards of the Convention; and

(l) Monitoring and implementation envisaged under article 19 should be carried out in full consultation and participation of persons with disabilities through their representative organizations.

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