

**NGO information to the United Nations
Committee on the Rights of Persons with Disabilities**

**Comments on the draft General Comment on the right of persons with disabilities to live independently and be included in the community (article 19)**

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Contents

[INTRODUCTION 2](#_Toc487214120)

[THE NATURE OF THE RIGHTS PROVIDED FOR IN ARTICLE 19 2](#_Toc487214121)

[STATE OBLIGATION RELATED TO DEINSTITUTIONALISATION 11](#_Toc487214122)

[Why are there still institutions? 11](#_Toc487214123)

[Prohibition of institutionalization 14](#_Toc487214124)

[Deinstitutionalization plans and strategies 15](#_Toc487214125)

[SUPPORTS AND SERVICES 16](#_Toc487214126)

[RELATIONSHIP WITH OTHER PROVISIONS OF THE CONVENTION 21](#_Toc487214127)

# INTRODUCTION

This written submission provides the UN Committee on the Rights of Persons with Disabilities (hereinafter “the Committee”) with observations on the Draft General Comment on the right of persons with disabilities to live independently and be included in the community (article 19 of the Convention on the Rights of Persons with Disabilities (hereinafter “the Convention”)), with particular focus on the enjoyment of this right by persons with intellectual and psychosocial disabilities.

The submission has been written by the Mental Disability Advocacy Centre (MDAC). MDAC is an international human rights organisation which uses the law to secure equality, inclusion and justice for people with mental disabilities worldwide. MDAC’s vision is a world of equality where emotional, mental and learning differences are valued equally; where the inherent autonomy and dignity of each person is fully respected; and where human rights are realised for all persons without discrimination of any form. MDAC has participatory status at the Council of Europe, and observer status at ECOSOC. For more information, please visit [www.mdac.org](http://www.mdac.org).

# THE NATURE OF THE RIGHTS PROVIDED FOR IN ARTICLE 19

As the CRPD Committee points out, Article 19 is a hybrid, as it provides for different categories of rights, being both civil and political, and economic, social and cultural in nature.

The **civil and political rights** are immediately applicable and a State will be in violation of the CRPD immediately upon ratification, unless they have already brought their laws, policies, practices and procedures into conformity with these Convention requirements.[[1]](#footnote-1)

The implementation of such rights goes hand in hand with the implementation of the economic, social and cultural rights. For example, where a State is failing in its obligation to provide adequate housing to all of its citizens who cannot provide it for themselves, Article 19(a) places an obligation on the State to progressively provide adequate housing for people with disabilities and an immediate obligation to ensure that people with disabilities have access to new housing provided for the general population on a basis of equality; but it does not require immediate guarantees of housing for all people with disabilities.

While not of immediate applicability, the guarantees of economic, social and cultural rights must be made in relation to the principle of progressive realization, which is incorporated in the CRPD in Article 4(2). Article 4(2) also incorporates an immediate obligation of conduct, even for economic, social and cultural rights: “each State Party undertakes to take measures… with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law” (emphasis added). By analogy with similar wording in Article 2(1) of the UN Covenant on Economic, Social and Cultural Rights, the obligation to take measures is not subject to progressive realisation – States must act “within a reasonably short time” after entry into force of the Convention. Although it is an obligation of conduct and not of result, the measures must be “deliberate, concrete and targeted as clearly as possible towards meeting the obligations” in the Convention.[[2]](#footnote-2) Similarly, the European Committee of Social Rights requires that measures fulfil three criteria: (i) a reasonable timeframe, (ii) measurable progress and (iii) financing consistent with the maximum use of available resources. States must take “practical action to give full effect to the rights recognized in the Charter”.[[3]](#footnote-3)

While State’s must take immediate measures to secure economic, social and cultural rights, it is for each State to determine what measures it will take (e.g. legislative measures providing explicit legal recognition of rights, provision of judicial remedies for violations through e.g. recognition of the justiciability of rights, administrative, financial, education and/or social measures). *It is also for the State to determine the specific timeframe in which such measures will be implemented.* However, Article 19 itself requires that any such measures be “effective and appropriate”. In the context of de-institutionalisation in particular, the measures must have clear time frames and benchmarks and include adequately funded strategies for de-institutionalisation in cooperation with people with disabilities.[[4]](#footnote-4)

The principle of progressive realisation does not apply to those elements of Article 19 which are civil and political in nature, particularly the rights to choice, and to equality and non-discrimination, including provision of reasonable accommodations.

**Non-discrimination** is a core element of Article 19. The non-discrimination aspect of the right to choice in Article 19(a) requires that people with disabilities have “the possibility to choose from the same range of options as other members of society, or to reject those options”. Services provided in an isolated, segregated setting do not meet the criteria of Article 19(b) whose purpose is “to prevent isolation or segregation from the community.” People with disabilities must be given the opportunity to take an active role in identifying and establishing community-based services for themselves. Where disability-specific or general healthcare and other services are already provided by the State, they must never be provided in a discriminatory manner. This requirement is immediately binding on ratification. So, if a State provides, for example, healthcare services to the general public in community-based clinics and hospitals but provides healthcare services for people with disabilities in segregating institutions, the State violates the prohibition of non-discrimination under Article 19(c) and under Article 5.

In MDAC’s view, the principle of progressive realisation requires forward movement and is therefore distinct from the **principle of non-retrogression** which prohibits measures that directly or indirectly lead to backward steps in the enjoyment of rights. Non-retrogression has been considered within the UN system in relation to other economic, social and cultural rights. The Special Rapporteur on Water, for example, describes a retrogressive measure as “one that, directly or indirectly, leads to backward steps in the enjoyment of human rights. Examples include raising the price of services disproportionately so that poor people can no longer afford water and sanitation, and letting infrastructure deteriorate due to a lack of investment in operation and maintenance”.[[5]](#footnote-5) In the context of Article 19 of the Convention non-retrogression prohibits, for example, any State action to reduce or remove general or disability-specific services from those who already benefit from them, to weaken legislative guarantees, or to undermine positive policies and practices. Non-retrogression requires that States do not allocate any additional resources towards forms of residence or service provision that violate Article 19 and, specifically, do not create new institutions or increase investment in existing institutions, for example, through refurbishment. The principle of non-retrogression is immediately binding on States on ratification.

The obligation is not absolute: the CESCR Committee has considered “retrogressive measures” in the context of progressive realisation and has stated that any such measures “would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the [Convention] and in the context of the full use of the maximum available resources”.[[6]](#footnote-6)

The principle of **progressive realisation** requires more of States than to simply refrain from taking or facilitating measures which might have a negative impact on people with disabilities: it includes an obligation to “take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities.”[[7]](#footnote-7) It therefore has immediate obligations of conduct: States must take effective and appropriate measures immediately with a view to achieving full realisation progressively of economic, social and cultural rights. It requires States to act “within a reasonably short time” and the measures must be “deliberate, concrete and targeted”. They must demonstrate measurable progress and financing consistent with maximum use of available resources.

The principle of progressive realisation cannot be used to deprive an obligation of all meaningful content[[8]](#footnote-8) and will almost invariably require use of resources and a wide range of specially tailored measures. Therefore, under Article 19(b), States have an obligation to progressively introduce new in-home, residential and other community support services specifically for people with disabilities and to progressively increase access to existing disability-specific services through, for example, expanding their geographical scope and putting in place accessibility measures. Failure to demonstrate positive action in this regard breaches the rights of people with disabilities under this article.

States are under an obligation to immediately secure a **minimum core content** of the rights under Article 19 CPRD. This is a distinct obligation, not subject to progressive realisation and goes beyond non-retrogression. Whether it has been met is defined by the number of people affected and the nature of the right in question. A State will be failing to provide the minimum core content of the right to live in the community if a significant number of individuals with disabilities are prevented from exercising choice about where and with whom to live on an equal basis with others or are obliged to live in a particular living arrangement (Article 19(a)); are denied access to specialised services to support living and inclusion in the community and prevent segregation (Article 19(b)); or are denied access to services and facilities for the general population on an equal basis and which are responsive to their needs (Article 19(c)).

The nature of the Article 19(a) right to choose where and with whom to live is a right of immediate effect and not subject to a minimum core content. The nature of the rights in Article 19(b) and (c) covers many supports and services but at a minimum it includes those necessary to ensure meaningful inclusion in the community with choices equal to others, such as access to essential primary healthcare, essential foodstuffs, basic shelter and housing, basic education, basis habilitation and rehabilitation, and basic support services such as in-home support, day services, life planning, personal assistance and support to family. [[9]](#footnote-9) The minimum core content of Article 19 must be understood to encompass the minimum core content of each and every support and service which is essential for people with disabilities to live independently in the community. Any other definition deprives the obligation of its meaning and content. The minimum core content of the rights under Article 19 cannot go below basic inclusion in the community through immediate release from segregation and provision of the minimum necessary services on an equal basis with others.

This definition of the minimum core content of Article 19 rights is without prejudice to the larger obligation to progressively provide greater access to such services and supports, greater levels of services, more diverse services and better quality services on an on-going basis towards complete inclusion and participation of people with disabilities in the community and full enjoyment by them of their rights. This requires, for example, increasing access to non-essential services such as cultural facilities provided by the State and promoting inclusion of people with disabilities into aspects of community life which are privately organised or provided such as restaurants, sports, hotels, and recreation centres.

In achieving respect for the minimum core content, a State must demonstrate that every effort has been taken to use all resources at its disposition in order to satisfy, as a matter of priority, those minimum obligations. Where there are severe resource constraints, a State’s duty to protect vulnerable society members assumes a greater importance. National resources as well as support from the international community, including European Union Structural and Investment Funds must be considered.

Reading Article 19 in conjunction with Articles 2 and 5, States also have an immediate obligation to provide **reasonable accommodation** to individual people with disabilities to ensure access to community-based services.[[10]](#footnote-10) The rights to equality and non-discrimination demand that such accommodations be provided without any considerations of progressive realisation. Reasonable accommodation plays a particularly significant role in ensuring the rights under Article 19(c) by improving the ability of people with disabilities to access services available to the general population.

States also have the obligation to ensure the rights in Article 19 by using a **maximum of available resources** – where the creation of specialised services is beyond the actual resource capabilities of a particular State, it may nonetheless be possible to make significant strides in improving access to general services which meet the specific needs of people with disabilities using the maximum of available resources through, *inter alia*, ensuring reasonable accommodations along with adopting general accessibility measures in conformity with Article 9.

.State must demonstrate that “every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”[[11]](#footnote-11) Further, “the duty of States parties to protect the vulnerable members of their societies assumes greater rather than less importance in times of severe resource constraints”[[12]](#footnote-12) and such vulnerable members of society (such as people with disabilities) must be protected by the adoption of relatively low-cost targeted programmes even in times of severe resource constraints.[[13]](#footnote-13)

The obligation to use the maximum of available resources to ensure that individuals, particularly vulnerable individuals, can exercise at least the minimum core content of all rights is to be read in the context both of resources existing within a State and those available from the international community (e.g. EU Structural and Investments Funds).[[14]](#footnote-14)

Taking into consideration this line of reasoning, we are suggesting a set of changes to the Draft General Comment on Article 19. They include both changes in relation to specific paragraphs of the Draft and to introducing new paragraphs.

**Paragraph 7:**

*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 independent living and being included in the community can only be realized if all civil, political, economic, 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. In the same time, states have the obligation to ensure the rights in Article 19 by using a maximum of available resources – where the creation of specialised services is beyond the actual resource capabilities of a particular State, it may nonetheless be possible to make significant strides in improving access to general services which meet the specific needs of people with disabilities using the maximum of available resources through, inter alia, ensuring reasonable accommodations along with adopting general accessibility measures in conformity with Article 9.*

*.State must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, minimum obligations. Further, the duty of States parties to protect the vulnerable members of their societies assumes greater rather than less importance in times of severe resource constraints and such vulnerable members of society (such as people with disabilities) must be protected by the adoption of relatively low-cost targeted programmes even in times of severe resource constraints.*

*The obligation to use the maximum of available resources to ensure that individuals, particularly vulnerable individuals, can exercise at least the minimum core content of all rights is to be read in the context both of resources existing within a State and those available from the international community (e.g. EU Structural and Investment Funds). 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.*

**Paragraph 40:**

*40. The Committee finds it important to identify minimum 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. The minimum core content of the rights under Article 19 cannot go below basic inclusion in the community through immediate release from segregation and provision of the minimum necessary services on an equal basis with others. 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;*

*(c) The right to live independently does not entail dependence on informal support from family and friends;*

*(d) To have access to support and services necessary to ensure meaningful inclusion in the community with choices equal to others, such as access to essential primary healthcare, essential foodstuffs, basic shelter and housing, basic education, basis habilitation and rehabilitation, and basic support services such as in-home support, day services, life planning, personal assistance and support to family*

*(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; to have access to each and every support and service which is essential for people with disabilities to live independently in the community and*

*(f) The possibility of living independently must not be negatively affected by measures taken to respond to economic constraints.*

**Paragraph 41:**

*41. States parties obligations have to reflect the hybrid legal character of the norm. The civil and political rights are immediately applicable and a State will be in violation of the CRPD immediately upon ratification, unless they have already brought their laws, policies, practices and procedures into conformity with these Convention requirements. The implementation of such rights goes hand in hand with the implementation of the economic, social and cultural rights. For example, one component of article 19 (a) is the right to choose one’s residence and where, how and with whom to live, which is immediately applicable. In the same time, where a State is failing in its obligation to provide adequate housing to all of its citizens who cannot provide it for themselves, Article 19(a) places an obligation on the State to progressively provide adequate housing for people with disabilities and an immediate obligation to ensure that people with disabilities have access to social housing provided for the general population on a basis of equality; but it does not require immediate guarantees of housing for all people with disabilities. Article 19 (b), the right to access individualised assessed disability support services, is a classic economic and social right. Article 19 (c), the right to avail community services and facilities, is an economic, social and cultural right, given that many community services, such as cinemas, public parks, theatres and sports facilities, serve cultural purposes. While not of immediate applicability, the guarantees of economic, social and cultural rights are subject to progressive realization, which is incorporated in the CRPD in Article 4(2).*

*Article 4(2) also incorporates an immediate obligation of conduct, even for economic, social and cultural rights: “each State Party undertakes to take measures… with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”. The obligation to take measures is not subject to progressive realisation – States must act within a reasonably short time after entry into force of the Convention. Although it is an obligation of conduct and not of result, the measures must be deliberate, concrete and targeted as clearly as possible towards meeting the obligations in the Convention.*

*It is for each State to determine what measures it will take (e.g. legislative measures providing explicit legal recognition of rights, provision of judicial remedies for violations through, recognition of the justiciability of rights, administrative, financial, education and/or social measures). It is also for the State to determine the specific timeframe in which such measures will be implemented. Article 19 itself requires that any such measures be effective and appropriate. In the context of de-institutionalisation in particular, the measures must have clear time frames and benchmarks and include adequately funded strategies for de-institutionalisation in cooperation with people with disabilities.*

**Paragraph 42**

*42. The principle of progressive realisation requires more of States than to simply refrain from taking or facilitating measures which might have a negative impact on people with disabilities. In order to achieve the realization of social and cultural rights, States parties must take steps to the maximum of their available resources (art. 2 (1) ICESC). The principle of progressive realisation includes an obligation to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. While full realization of the goals may be achieved progressively, steps towards it must include effective and appropriate measures which must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means. They must demonstrate measurable progress and financing consistent with maximum use of available resources. 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.*

*The principle of progressive realisation cannot be used to deprive an obligation of all meaningful content and will almost invariably require use of resources and a wide range of specially tailored measures. Therefore, under Article 19(b), States have an obligation to progressively introduce new in-home, residential and other community support services specifically for people with disabilities and to progressively increase access to existing disability-specific services through, for example, expanding their geographical scope and putting in place accessibility measures. Failure to demonstrate positive action in this regard breaches the rights of people with disabilities under this article.*

**Paragraph 43:**

*43. An exemption from progressive realization regarding the rights under article 19 (a), (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. This is a distinct obligation, not subject to progressive realisation and goes beyond non-retrogression. Whether it has been met is defined by the number of people affected and the nature of the right in question. A State will be failing to provide the minimum core content of the right to live in the community if a significant number of individuals with disabilities are prevented from exercising choice about where and with whom to live on an equal basis with others or are obliged to live in a particular living arrangement (Article 19(a)); are denied access to specialised services to support living and inclusion in the community and prevent segregation (Article 19(b)); or are denied access to services and facilities for the general population on an equal basis and which are responsive to their needs (Article 19(c)). 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 fulfil 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.*

*This definition of the minimum core content of Article 19 rights is without prejudice to the larger obligation to progressively provide greater access to such services and supports, greater levels of services, more diverse services and better quality services on an on-going basis towards complete inclusion and participation of people with disabilities in the community and full enjoyment by them of their rights. This requires, for example, increasing access to non-essential services such as cultural facilities provided by the State and promoting inclusion of people with disabilities into aspects of community life which are privately organised or provided such as restaurants, sports, hotels, and recreation centres.*

*In achieving respect for the minimum core content, a State must demonstrate that every effort has been taken to use all resources at its disposition in order to satisfy, as a matter of priority, those minimum obligations. Where there are severe resource constraints, a State’s duty to protect vulnerable society members assumes a greater importance. In assessing the compliance with this obligation consideration must be given both to national resources, as well as to support from the international community, including European Union Structural and Investment Funds and donations through foundations.*

**Paragraph 44:**

*44. The duty of progressive realization also entails a presumption against retrogressive measures in the enjoyment of economic, social and cultural rights. The principle of non-retrogression which prohibits measures that directly or indirectly lead to backward steps in the enjoyment of rights. In the context of Article 19 of the Convention non-retrogression prohibits, for example, any State action to reduce or remove general or disability-specific services from those who already benefit from them, to weaken legislative guarantees, or to undermine positive policies and practices. Non-retrogression requires that States do not allocate any additional resources towards forms of residence or service provision that violate Article 19 and, specifically, do not create new institutions or increase investment in existing institutions, for example, through refurbishment. The principle of non-retrogression is immediately binding on States on ratification. This obligation is not absolute, but 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.*

**Paragraph 45:**

*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.*

**Paragraph 46:**

*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 non-discrimination aspect of the right to choice in Article 19(a) requires that people with disabilities have “the possibility to choose from the same range of options as other members of society, or to reject those options”. Services provided in an isolated, segregated setting do not meet the criteria of Article 19(b) whose purpose is “to prevent isolation or segregation from the community.” People with disabilities must be given the opportunity to take an active role in identifying and establishing community-based services for themselves. Where disability-specific or general healthcare and other services are already provided by the State, they must never be provided in a discriminatory manner. This requirement is immediately binding on ratification. So, if a State provides, for example, healthcare services to the general public in community-based clinics and hospitals but provides healthcare services for people with disabilities in segregating institutions, the State violates the prohibition of non-discrimination under Article 19(c) and under Article 5. The duty to provide reasonable accommodation (art. 5 (3) CRPD) is also not subjected to progressive realization. In the context of Article 19 this means that States have an immediate obligation to provide reasonable accommodation to individual people with disabilities to ensure access to community-based services. Reasonable accommodation plays a particularly significant role in ensuring the rights under Article 19(c) by improving the ability of people with disabilities to access services available to the general population.*

# STATE OBLIGATION RELATED TO DEINSTITUTIONALISATION

## Why are there still institutions?

Over time it has become obvious that institutions are inadequate places of living and offering services for people with disabilities. Many reports have documented and exposed devastating conditions and treatment that persons in institutions can be exposed to (see for example reports of human rights organizations such as the *Disability Rights International[[15]](#footnote-15), Mental Disability Advocacy Center (MDAC)[[16]](#footnote-16), Amnesty International[[17]](#footnote-17), Human Rights Watch[[18]](#footnote-18)* and others). This included various forms of abuse and neglect, outdated methods of treatment, drugs abuse, fixation and isolation, incompetent or inadequate staffing, overpopulation, lack of personnel, bad and inhumane conditions, failures in the review of complaints and victimization of persons who file complaints, including users and staff members.

This raises questions in relation to why are there so many countries around the world where people with disabilities continue to be institutionalized. MDAC’s more than 10 years experience in Central and Eastern Europe shows that the high levels of institutionalization are due to a lack of political will in relation to developing alternative services, combined with the stigma and prejudices existing in relation to living with disabilities. It seems that for many societies and decision-makers institutions are the only envisioned option.

While there is an upfront cost to developing new community-based services, costs are reduced in the medium term. Moreover, more and more research shows that, in terms of cost-effectiveness, institutions are not necessarily saving states money, particularly not on the long term.[[19]](#footnote-19) Besides, when assessing cost effectiveness, careful consideration needs to be given not only to financial resources, but also to the impact on the rights and quality of life of people with disabilities. Also, with the right support, people with disabilities can make concrete contributions to the economy and society.[[20]](#footnote-20)

In institutions there has been observed also the development of a working culture which has, on one side, extremely detrimental effects on the rights of people living there, and on the other side has negative impacts on the staff as well- they often complain of hard working conditions, high expectations with little resources and lack of adequate training, particularly when it comes to offering treatment- when treatment is the reason why people with disabilities are said to be in need of institutionalization.[[21]](#footnote-21)

Importantly, many people with disabilities end up in institutions because they do not have a support network, being abandoned at birth and having no family or circle of friends willing to support them, in the most basic sense, in developing abilities which would help them integrate in communities and live independently- such as developing basic skills and receiving any form of education. Secondly, in many states there is a virtual lack of alternatives, or alternative services are highly insufficient, being offered by NGOs which do not receive state funding.

In the same time, there are countries which have not developed a culture of providing support and services to people with disabilities in institutional settings. However, simply because people physically live in communities does not mean they are not isolated and/or segregated, nor that they are living independently or are included in the community. That is because they are denied autonomy and choice, are sometimes deprived of liberty by families or other community members, do not have access to supports and services and are vulnerable to a wide variety of other human rights abuses, including physical, psychological and mental abuses.[[22]](#footnote-22)

Taking into consideration this line of reasoning, we are suggesting the following changes:

**Paragraph 20:**

*20. In some State parties, institutionalisation of people with disabilities has remained entrenched in the system with little or no real effort being made towards supporting people to live independently in communities. This impacts people with all level of support needs and it is based on stigma and prejudices and on false assumptions that enabling independent and community living is necessarily more expensive than institutional care. In other 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.*

*There are also other State parties which do not traditionally institutionalise people with disabilities. That does not however directly mean that there the right to living independently and being included in the community is respected for all people with disabilities. Lack of institutionalisation does not mean implementation of Article 19. People can be isolated and/or segregated while physically in the community as well, where they can be vulnerable to abuses as well, with experience showing they can be, in such settings, denied of autonomy and choice, deprived of liberty and subjected to other human rights abuses.*

**Paragraph 48:**

*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, policies and structures 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, policies and structures 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.*

## Prohibition of institutionalization

Article 19 is closely linked to other Convention articles, including those containing obligations of immediate result, such as Article 14 and the right to liberty and security of the person which requires the abolition of all forms of deprivation of liberty based on the existence of an impairment,[[23]](#footnote-23) including institutionalisation.[[24]](#footnote-24) This has been clearly states by the CRPD Committee in this Draft General Comment in several paragraphs, such as paragraph 16 (“Institutionalized settings are not compliant with the concepts of independent and community living”), paragraph 19 (“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”).

There are however certain statements where the Draft General Comment seems to suggest there would be, under the Convention, a right to choose institutionalisation (specifically Paragraph 47); the Draft General Comment is also failing to define clearly what a “residential” setting is under Article 19 (b), so as for it not to be interpreted as including institutions (specifically paragraph 28).

Article 19 is closely linked to all articles of the Convention, including Article 3, which states that the principles of the present Convention shall include:

“(a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

(b) Non-discrimination;

(c) Full and effective participation and inclusion in society”.

In MDAC’s opinion, this is to mean the Convention sets out, in Article 19, a right to live independently and be included in the community, and includes the right to choose where and with whom to live, autonomy rights which cannot be enjoyed unless legal capacity is respected. Article 19 also includes the obligation on governments to ensure that all services including housing, transport, education and health care are accessible to persons with disabilities. It cannot however be interpreted as awarding any right to segregation, irrespectively of whether such right relates to education, health or living spaces.

In this line of reasoning, MDAC suggests the removal of **paragraph 47**, which states:

 *~~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.~~ The right to decide where, how and with whom to reside cannot be interpreted as awarding people the right to choose to live in places where they are subjected to abuses. States can never defend their choice to continuing investing in institutions by claiming that the people – to which they are not offering other alternatives- choose to live in institutional settings.*

MDAC also suggests the following modifications for **paragraph 28**:

*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.~~ Allowing residential services cannot be interpreted as allowing institutionalisation. Residential services provide temporary care, on the basis of free and informed consent, and only in as much as they do not promote the isolation or the segregation of people from community. Other community support services include personal assistance services or similar person-directed/user-led support.*

**Paragraph 38:**

*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, 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.~~ Institutionalisation of any type remain in violation of Article 19 and it shall not be justified by financial reasons or other practical impediments State parties might raise.*

## Deinstitutionalization plans and strategies

Deinstitutionalisation plans and strategies must include reasonable timeframes. There examples of countries which, when creating such strategies, have assumed the obligation to implement them in very long periods of time. This can make such strategies almost entirely meaningless. For example, Hungary has adopted at one point a DI strategy[[25]](#footnote-25) that had a 30-year implementation period (2011-2041). The CRPD Committee must make it clear in this General Comment that such timeframes are inacceptable under the CRPD.

We suggest therefore adding a relevant observation on this issue in **paragraph 56**.

*56. States parties should adopt a strategy for de-institutionalization. De-institutionalization includes the duty to implement structural reforms and be adequately funded. 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. Such strategies must include well-established and reasonable timeframes and benchmarks, which should be considered in light of the obligations to immediately implement civil and political rights and to consider the principles of progressive realisation and non-retrogression in relation to economic, social and cultural rights. Deinstitutionalisation policies must also be inclusive of all persons with disabilities, regardless of their impairments or level of support needs.*

# SUPPORTS AND SERVICES

Access to supports and services is essential to ensure the right to living independently and being included in the community, irrespectively if that is in relation to deinstitutionalisation plans or in settings where institutional care is not the primary solution envisioned by state authorities.

People with intellectual and psychosocial disabilities might need particular types of support and services, many of which are lacking from schemes targeting people with disabilities- which might only focus on the needs of people with physical or sensory impairments. It is therefore necessary to always include, when discussing supports and services, reference to items such as community based mental health care centres, day care centres which offer habilitation and rehabilitation, supported decision-making mechanism etc.

MDAC’s experience shows that access to housing is one of the most common challenges in countries across Central and Eastern Europe when it comes to trying to implement deinstitutionalisation strategies. That is because people do not have access to where they could physically move, which is of course a basic requirement in order to leave an institution. This situation is sometimes caused not because of lack of housing, but because of lack of taking into consideration the specific situation of institutionalized people with disabilities when creating the conditions to be met in order to access social housing. Common requirements include having full legal capacity and not having family members. Many people with disabilities living in institutional settings are however deprived of legal capacity. In the same time, even if they have family members, many times they do not keep in touch and are in the institutional setting because they cannot live with the family members. Therefore requiring not to have a family member is unreasonable.

Moreover, access to social housing is sometimes conditioned on the place of residence of the person. For institutionalised people with disabilities that can be extremely problematic from two perspectives. One situation is that where many of this people have, as a place of residence, the institution, which is often located in an isolated place. Conditioning access to social housing on the place of residence can therefore mean that when deinstitutionalisation strategies are being implemented, hundreds of people are suddenly competing for the few opportunities of social housing in a small community. Another situation is that where people have, as a place of residence, the place they were born, but where they have never been, or go rarely and to which they have no other connection. There are institutions, in countries such as Bulgaria, Moldova and Romania, where people who live in institutions do go out for shopping or for work and manage to establish some sort of connection within communities. Denying them access to social housing in those communities and forcing them to go back to a place to which they are connected only because they were born there- and where they have no support network- can be an important obstacle towards inclusion in the community. It also disregards the already established support-networks, which are essential in transition processes.

In the same time, it is important to correctly manage existing support-network and services. For example, when the person has people they trust they can be involved in offering support in decision-making, which reduces the costs of the services the state will need to award for that specific person. However, such an approach is not correct when the role of personal assistant is being realised by a family member or a partner. The state needs to ensure financial resources for such services. It can choose to facilitate payment and training of family members, but it cannot expect family members to replace the state’s obligations.

It is also pertinent to recall here the statement of the OHCHR that “[l]iving independently does not mean living alone or in isolation. Rather, it means exercising freedom of choice and control over decisions affecting one’s life with the same level of independence and interdependence within society on an equal basis with others. Consequently, article 19 refers to ‘living independently and being included in the community’ as one right, where autonomy and inclusion are mutually reinforcing and jointly avoid segregation.” In other words, ensuring autonomy and choice alone are not sufficient to avoid violating Article 19: choice must be ensured ‘on an equal basis with others’ and measures in this regard must be accompanied by active measures to secure inclusion in the community such as the provision of necessary supports and access to existing general services in the community. Ipso facto, segregation in institutions does not fulfil this obligation. Similarly, the OHCHR has identified support services as “essential” to enable people with disabilities to live independently and be included in the community and as an “indispensable element of deinstitutionalization”.

In relation to access to justice for violations of rights, we must underline that MDAC’s experience shows that sometimes cultural norms and gender based stereotypes create obstacles in accessing justice for women, particularly in relation to allegation of gender-based violence.[[26]](#footnote-26)

On the basis of all this observations, MDAC makes a series of suggestions in relation to changing the text of Draft General Comment on Article 19.

**Paragraph 15:**

*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. And most importantly, it should not be interpreted as meaning the person has to live without any form of support. Rather, it should be regarded as the freedom to choice and control, as enshrined in article 3 (a) of the Convention, while being provided with support services of all types and being enabled to live in a barrier-free society. 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. The person shall also receive all support they need to enjoy such independence.*

*(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, community-based mental health services, 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. (…)*

*(d) Personal assistance refers to person-directed/ and 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.*

**Paragraph 24:**

*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, choosing in what form to receive the support the person might need, as well as way of life and lifestyle of a person, covering private and public spheres in a daily and long term dimension.*

**Paragraph 26:**

*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 existing alternatives and to social interactions, to others within the respective community where one lives and can freely pursue one’s personal development and fulfilment. It is necessary to, on one side, acknowledge the right to make decisions, while also accepting that people with disabilities might need support in decision-making. Access to supported decision-making mechanisms (e.g. professional or informal circles of support, personal ombudspersons, representative agreements etc.) must therefore be guaranteed.*

**Paragraph 29:**

*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, specialists in facilitating communication for persons with intellectual disabilities, 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.*

**Paragraph 57:**

*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. For example, access to housing should not be conditioned on the person having full legal capacity, or having no family members, or being born in a certain jurisdiction. Public buildings and spaces and all forms of transport must be designed in a way to accommodate the requirements of all persons with disabilities.*

**Paragraph 58:**

*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. Importantly, support offered by family members or partners should not be seen as always replacing the need for state funded support, and, if it does, family members should in many cases receive payment through state funding. For example, while family members could choose to be involved for free in circle of support in decision-making, if they are also offering regular personal assistance to the person who needs it they should receive payment from state funds for the latter. Independent living is about the right to live independently and not about maintaining the regime of ‘Care’.*

**Paragraph 59:**

*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 support needs ~~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.*

**Paragraph 60:**

*60. ~~Cash transfers~~ Financial benefits 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~~ benefits often recognise disability-related expenses and facilitate the inclusion of persons with disabilities in the community. ~~Cash transfers~~ Financial benefits 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.*

**Paragraph 61:**

*61. ~~Cash transfers~~ Financial benefits 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~~ obstacles 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.*

**Paragraph 62:**

*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 whether they are deprived or not of legal capacity or 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.*

**Paragraph 67:**

*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. Careful considerations in ensuring access to justice must also be given to cultural and gender based stereotypes and to their intersectionality with disability to ensure non-discrimination- particularly when it comes to allegations of gender-based violence taking place in institutional settings. Moreover, States Parties should include in national legislation express provisions on the right to independent living and being included in the community. This could facilitate access to justice for people seeking to enforce this right before courts.*

# RELATIONSHIP WITH OTHER PROVISIONS OF THE CONVENTION

MDAC considers the section on the link with the other articles of the Convention from the Draft General Comment on Article 19 to be of significant importance. It therefore finds it relevant to make suggestions for amendments of several of the articles. The suggestions are based on our experience in monitoring, research and litigation underwent for the promotion of the rights of people with intellectual and psychosocial disabilities.

In MDAC’s experience many people with a long history of living in an institution need rehabilitation, as well as habilitation, which is to refer to acquiring skills one never had. That is because people, particularly when living in institutional settings from a very young age, do not have basic skills such as cleaning on their own, cooking or making the most basic choices (e.g. What to wear, what cultural activities to be involved in etc.). In some environments cases can be even more extreme. For example, we have seen cases where people with minor physical impairments cannot eat on their own because the staff of the institution found it took too much effort to provide cutlery and award more time for meals- it takes much less time to feed a person, particularly if that is done while ignoring their indications. For this reason we insist on discussing about both habilitation and rehabilitation in the Draft General Comment.

The right to respect for home and the family (Article 23) is a rights people living in institutions often refer to, as many of them face significant obstacles in trying to form families. That is because living in an institution means less access to meeting people and very restrictive routines and rules which often do not allow people to sleep in the same room with a person of the opposite sex, force them to take contraception, do not allow them to live with a child in the institution. That is why we advise that this Draft General Comment does not discuss only the problems faced by families who have children or adults with disabilities in their care.

**Paragraph 70:**

*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. It is also important to notice that institutionalization is a form of discrimination. Persons with disabilities who are facing discrimination in relation to article 19 must have effective and affordable legal remedies at their disposal.*

**Paragraph 71:**

*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. Therefore, when implementing the right to live independently and be included in the community, particular attention should be paid to gender equality and gender based discrimination. Deinstitutionalization strategies must include habiltiative and rehabilitative programs for victims of gender- based violence (such as rape, forced abortions, forced gynaecological interventions etc. in institutionalized settings).*

**Paragraph 84:**

*84. The right to independent and community living is intimately linked with the right to respect for home and the family ~~family for children and parents with disabilities~~ (art. 23). If community based support and services are not in place, this may create difficulties for people with disabilities to form families of their own, to marry and to have children; it can also place financial pressures and other constraints for the family of persons with disabilities who want to leave with their families and are receiving support from them; the rights enshrined in article 23 of the Convention are essential as well to prevent children from being taken away from their families and being institutionalized –whether because the child has a disability or one or more family members have a disability-, as well as to support families in community living. States parties should provide information, guidance and support to families which include people with disabilities in upholding their children’ rights and promote inclusion and participation in the community so that families are in a better position to contribute to independent and community living.*

**Paragraph 87:**

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

**Paragraph 88:**

*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 and must therefore be avoided.*

**Paragraph 90:**

*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 and that States do not adopt legislation that impact on people’s voting rights (e.g. legislation according to which people deprived of legal capacity cannot vote).*

**Paragraph 94:**

*94. (…)*

*(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, community based mental health services, supported decision-making mechanisms etc.*

1. See, for example, CRPD General Comment No. 1 at para. 30. [↑](#footnote-ref-1)
2. CESCR Committee’s General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 2. [↑](#footnote-ref-2)
3. *International Federation for Human Rights (FIDH) v. Belgium*, Complaint No. 75/2011, decision adopted 18 March 2013 at para. 147; and *Autism Europe v. France*, Complaint No. 13/2002, decision adopted 7 November 2003 at para. 53. [↑](#footnote-ref-3)
4. See, for example, the Committee’s Concluding Observations on Hungary (CRPD/C/HUN/CO/1) as well as those on Australia (CRPD/C/AUS/CO/1), Austria (CRPD/C/AUT/CO/1), El Salvador (CRPD/C/SLV/CO/1), Paraguay (CRPD/C/PRY/CO/1), and China (CRPD/C/CHN/CO/1 and Corr.1). [↑](#footnote-ref-4)
5. Report of the Special Rapporteur on the human right to safe drinking water and sanitation, Catarina de Albuquerque, 11 July 2013, A/HRC/24/44 at para. 14. [↑](#footnote-ref-5)
6. CESCR General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 9. [↑](#footnote-ref-6)
7. CESCR General Comment No. 5: Persons with disabilities of 1 January 1995 at para. 9. [↑](#footnote-ref-7)
8. As underline by the CESCR Committee in General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 9. [↑](#footnote-ref-8)
9. As underline by the CESCR Committee in General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991. For a useful description of options falling within State discretion in terms of disbursing funds and covering the costs of support services, see OHCHR Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37 of 12 December 2014 at para. 41. [↑](#footnote-ref-9)
10. This position is supported by the OHCHR: see OHCHR Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37 of 12 December 2014, para. 48. [↑](#footnote-ref-10)
11. CESCR Committee’s General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 10. [↑](#footnote-ref-11)
12. CESCR Committee’s General Comment No. 5: Persons with disabilities, of 1 January 1995 at para. 10. [↑](#footnote-ref-12)
13. CESCR Committee’s General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 12. [↑](#footnote-ref-13)
14. CESCR Committee’s General Comment No. 3: The nature of States parties’ obligations (Art. 2, par.1) of 1 January 1991 at para. 13. See also CESCR Committee’s General Comment No. 5: Persons with disabilities of 1 January 1995 at para. 13. [↑](#footnote-ref-14)
15. http://www.driadvocacy.org/media-gallery/our-reports-publications/ [↑](#footnote-ref-15)
16. http://mdac.org/en/resources [↑](#footnote-ref-16)
17. https://www.amnesty.org/en/latest/research/ [↑](#footnote-ref-17)
18. https://www.hrw.org/publications [↑](#footnote-ref-18)
19. See European Network on Independent Living. (2014). *Comparing the Cost of Independent Living and Residential Care A Survey by the European Network on Independent Living*, available at <http://www.enil.eu/wp-content/uploads/2012/06/Cost-survey_FINAL.pdf>; TheSouthern Oklahoma Resource. *Center Institutional vs. Community Services for Individuals with Intellectual/Developmental Disabilities*, available at <https://www.ok.gov/governor/documents/FAQ%20Community%20Services%20-%20NORCE-SORC.pdf>; [Knobbe CA](https://www.ncbi.nlm.nih.gov/pubmed/?term=Knobbe%20CA%5BAuthor%5D&cauthor=true&cauthor_uid=7779348) et. al. *Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors*. American Journal of Mental Retardation 1995 Mar;99(5):533-41. Mansell J, Knapp M, Beadle-Brown J and Beecham J. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 1: Executive Summary. Canterbury: Tizard Centre, University of Kent, available at <https://www.kent.ac.uk/tizard/research/research_projects/DECLOC_Volume_1_Exec_Summary.pdf>; David Tobis. (2000). *Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union*, The World Bank, available at http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172671461088/MovingFromResTobis.pdf [↑](#footnote-ref-19)
20. See for example Bulgarian Center for Not-for-Profit Law. (2014). *Cost Benefit Analysis of Supported Decision-Making,* available at http://bapid.com/bapid/wp-content/uploads/2014/08/SDM\_report\_engED.pdf. [↑](#footnote-ref-20)
21. See Parker, Camilla & Clements, Luke.(2012). *The European Union Structural Funds and the Right to Community Living.* Equal Rights Review; (2011). *Out of Sight. Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia*. Mental Disability Advocacy Center and the Association for Social Affirmation of People with Mental Disabilities (SHINE); Caderyn J. Gaskin, Stephen J. Elson and Brenda Happell, ‘Interventions for Reducing the Use of Seclusion in Psychiatric Facilities’, British Journal of Psychiatry 191 (2007): 298; Sjostrom, Stefan. (2006). *Invocation of coercion context in compliance communication — power dynamics in psychiatric care*. International Journal of Law and Psychiatry. p. 38. [↑](#footnote-ref-21)
22. See, for example, the following MDAC’s reports: *Legal Capacity in Kenya* (March 2014), available at <http://mdac.org/sites/mdac.org/files/mdac_kenya_legal_capacity_9apr2014.pdf>; *Mental Health and Human Rights in Ugandan communities* (December 2014), available at <http://www.mdac.org/sites/mdac.info/files/mental_health_human_rights_in_ugandan_communities.pdf>; [↑](#footnote-ref-22)
23. OHCHR Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37 of 12 December 2014 at para. 8. [↑](#footnote-ref-23)
24. “The right of people with disabilities to live independently and be included in the community”, Council of Europe Commissioner for Human Rights Issue Paper, published June 2012 at p.31-32. [↑](#footnote-ref-24)
25. Strategy 2011-2041:

<http://fszk.hu/wp-content/uploads/2015/06/Kormanyhatarozat-es-Strategia-a-fogyatekos-szemelyek-szamara-apolast-gondozast-nyujto-szocialis-intezmenyi-ferohelyek-kivaltasarol.pdf> [↑](#footnote-ref-25)
26. Our monitors in Uganda report complaints of women in relation to lend cases tend to be neglected by authorities. In Moldova we saw authorities not initiating allegations submitted by women on gender-based violence as they found them not credible (see OHCHR, MDAC et. al. (2015). *Study on Human Rights of People with Intellectual and Mental Disabilities in the Republic of Moldova*, available at http://www.mdac.org/sites/mdac.info/files/moldova\_report\_2015\_english.pdf). [↑](#footnote-ref-26)