

Live Independently and Being Included in the Community

Submission to the UN Committee on the Convention on the Rights of Persons with Disabilities:
Draft General Comment No. 5 on Article 19.

Easy-to-read summary



Inclusion Europe is an organisation that defends the rights of people with intellectual disabilities and their families in Europe.

Inclusion Europe wants you to think about these topics in the General Comment:

Everyone should be able to live independently and be included in society.

Independent living is important in many parts of life.

Independent living means that people with intellectual disabilities can choose with whom and where to live.

They also can:

- Live in the community.
- Decide how they want to spend their time.
- Have the same experiences as all other people.

For example, independent living has to do with:

- **Legal capacity.**

Legal capacity is when you can make a decision or a choice.

For example when you decide to buy something, to live somewhere or to marry someone.

- Education.
- Work.

Everyone has to be able to choose where to live and with whom.

This choice has to be made possible with the help of supported decision-making.

Supported decision-making means that people with intellectual disabilities can make life decisions with the support of another person without disabilities.

People with intellectual disabilities are particularly vulnerable to institutionalisation

Institutions are dangerous and are against human rights.

Institutions are places where people with intellectual disabilities live with apart from other people.



This is what we call “separated”.

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Institutions are places where you cannot decide about your life, but where someone else decides instead.

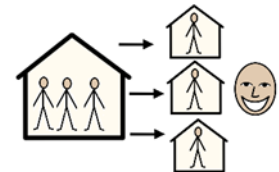
People with intellectual disabilities often live in institutions against their will.

States have to support living in the community and being independent.

State should provide support in the community as fast as possible.

We do not want to go back to the old ways, for example institutions. This would be discriminating people with intellectual disabilities.

Institutionalisation needs to end because it is not good for people.



People with intellectual disabilities need to choose where to live and be sure that their choice is heard.

This choice must help people to live in a place where they are free.

This choice must be based on:

- Access to information
- Real options
- Experience with living in the community

The right to choose has to give the person more inclusion.

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People with intellectual disabilities need help
after they lived in institutions.

They need help to be included in the community.

They need help to deal with bad experiences in institutions,

Sometimes we can see flats and homes where people with
intellectual disabilities are in the community,
but no able to make choices about their lives.

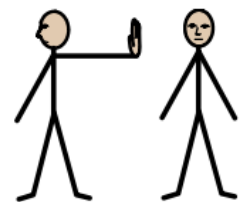
People with disabilities and families
should look at the new services,
to make sure the new services are inclusive.

We want to make sure that people will not have to
go back into institutions again.

People with disabilities should be able to complain
when they are **discriminated** against.

Discrimination means that you are treated unfairly
or that you do not get the chances you deserve.

It is discrimination when it happens
because of your disability.



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It can also happen to other people.

For example because people have a different skin colour, age etc.

Children with disabilities have the right to grow within a family.

Families sometimes need help with caring for children.



Families are very important for people with intellectual disabilities.

A lot of members in family can help, for example:

- parents,
- brothers and sisters,
- grandparents,
- and other family members.

They help people with intellectual disabilities
when they need them.

They also help people with intellectual disabilities
to become more independent.

Families sometimes protect people with intellectual disabilities too
much.

It is important that families get education about independent living.

Families also need to get more help from States.

Introduction

- Inclusion Europe is the association of people with intellectual disabilities and their families in Europe. We have **71 members in 38 countries**, and we represent more than 7 million people in Europe. Our members include organisations of people with intellectual disabilities and their families at national, regional and local level.

We fight for the recognition of equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of life. As a European association, we work in many different areas which our members have identified as important to them.¹

The right to live independently and be included in the community has been recognised as one of the key areas to achieve participation on an equal basis with others.
- Living in an institution is a human rights violation, as it denies the fundamental rights of people on citizenship, personal control, personal privacy, decision-making and inclusion. This includes possible physical and pharmacological restraints, psychiatric interventions, involuntary treatments and measures, such as sterilization, forced contraception, or abortion.

The general comment must be a clear order towards Member States that institutions are a harmful practice that leads to the victimisation of people who are forced to live there. Member States must plan their closure as well as the development of community based services and inclusive general services.

As long as countries keep institutions open, there will be incentives for people with disabilities to be institutionalised and there will be fewer resources to develop community-based services.
- Inclusion Europe wants to highlight that while working on the transition of service models from institutionalised to community-based, States parties must focus on the support-needs of the people with disabilities concerned.

It is essential that people with disabilities receive adequate assistance regarding social inclusion on a daily basis.

Also, a **previous life in an institution is likely to leave people victimised by experiences of violence, abuse or by the experience of non-recognition of their will and preferences.** It is not enough to move people physically from one service to another, but the necessary trauma support needs to be provided as well.

¹ Inclusion Europe thanks all its members for their inputs during the drafting process that greatly improved this contribution. This internal participation has been ensured by the organisation of a CRPD round table during our annual conference as well as a webinar on the draft general comment.

4. Inclusion Europe wants to highlight in this paper the positive role of family members in enabling their relatives to live independently, and the need for families to be supported to achieve this goal.

Families are a central actor in the learning of independent living skills and in the development of people with disabilities through transitional periods from childhood to adulthood.

However, the lack of support they face negatively impacts on the social and economic possibilities of all family members, including those with a disability.

We are seriously concerned about the **institutionalisation of many children with disabilities** who are deprived from their fundamental right to grow up in a family environment.

We are also preoccupied by the **isolation of people with complex support needs and their families**, suffering from a blatant lack of support.

General Comments

5. Inclusion Europe welcomes the holistic interpretation of Article 19 and considers all the elements of the draft General Comment (hereinafter “draft GC”) as essential to ensure its full implementation. Together with article 12, Article 19 constitutes the CRPD’s cornerstones and relate to many other aspects of life as outlined many times in the draft GC.²
6. Inclusion Europe applauds the emphasis put on the universality of the right to live independently and being included in the community in the draft GC (paragraphs 8 and 20). Inclusion Europe strongly advocates for an implementation of this right for all persons with disabilities, including persons with complex support needs who are often denied the right to live with others because they are presumed not to be able to live in the community.
7. Inclusion Europe very much welcomes the clear recognition of misallocation of resources towards institutions (paragraph 65) as a violation of the right to live independently and being included in the community.
We are concerned that institutions may be maintained only because of the economic and political interests and influence of service providers and their staff.
8. **Paragraph 11**
Inclusion Europe supports the concern of the Committee regarding the situation of children with disabilities facing institutionalisation and separation from their families.
The draft GC could further strengthen State parties’ obligation to provide families with an adequate support to avoid these situations of blatant violation of human rights.

² Inclusion Europe pointed out this intersectionality in its submission of the key issues for a General Comment on Article 19.

The importance for children to grow up in their families, enshrined in the Convention on the Rights of the Child, should be mentioned in the paragraph.

Finally, the paragraph should highlight the need for support when family care breaks down in the form of e.g. foster care or other adequate alternatives for the children.

Addition to paragraph 11Article

7 of the Convention on the Rights of the Child (hereinafter "CRC) establishes the right of children to know and be cared for and by their families. Article 9 of the CRC enshrines the right of children not to be separated from their parents unless it is necessary for the best interest of the child. To ensure the full enjoyment by children of these rights, States Parties have a duty to assist family members in their duties and facilitate the development of services as guaranteed by article 18. However, article 20 declares that if this family environment is absent or no suitable for children, foster or alternative care must be provided for by States. 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 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.

9. Paragraph 14

The General Comment needs to address relevant barriers preventing the implementation of article 19. Legal capacity and access to justice are essential to be able to defend one's right to live independently before a court. It is essential that lodging a complaint is accessible and a safeguard to such risk.

Addition to paragraph 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) and lack of accessible juridical mechanisms to challenge the deprivation of legal capacity/ decision of a guardian (interrelation with article 13);*
- 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 as well as a lack of support for family carers;*
- 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 and lack of implementation, and monitoring of the existing ones;*
- f. Negative attitudes, stigma and stereotypes that prevent persons with disabilities and more particularly people with complex support needs 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;*
- 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. Misallocation of funds towards the creation or the maintenance of institutional care services.*
- ~~l.~~ 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)).*

10. Paragraph 41

Inclusion Europe strongly supports the statement on the interrelation, interdependence and indivisibility of all human rights (paragraph 7) and more generally the acknowledgement of the hybrid aspect of article 19.

However, paragraph 41 of the draft GC should be further clarified as it distinguishes the nature of the right to choose from the provision of both disability-specific services and inclusive general services in the community.

The right to choose would be meaningless without the existence of adequate services to choose from, as pointed out by the draft GC itself (paragraph 40(b)).

It should be clearly stated that State Parties have to plan immediate closure of institutions as well as the development of services in the community. Immediate steps to develop new services should be taken by the States.

Addition to paragraph 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. Progressive realisation entails the immediate obligation to plan strategies and allocate resources to develop community based services and to make existing general services inclusive. State parties shall take immediate steps towards the creation of these services.

11. Paragraph 44

Inclusion Europe is concerned by the possibility of retrogressive measures mentioned in the draft GC (paragraph 44 and 45). Despite the safeguards raised in the text regarding general cases of prohibition, we are concerned with the way it could potentially be interpreted by State parties.

We strongly believe that **accepting retrogressive measures would be a threat and a serious impediment to the realisation of article 19.**

Change to paragraph 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. Such measures deprive people with disabilities of the full enjoyment of right to live independently and being included in the community. As a matter of consequence, retrogressive measures constitute a violation of article 19.~~

12. Paragraph 47

Inclusion Europe is alarmed about the interpretation of the right to choose in the draft GC and the way it could be interpreted by the States Parties as a mandate to postpone or hinder the deinstitutionalisation process and the closure of institutions. They may as well as keep investing money in institutional care to satisfy the so-called “decision to live in institutional care settings” instead of ensuring that a real choice exists for every person with disability.

This paragraph **legitimises institutions and thus contradicts the other strong statements against institutions and the way they violate the right of persons with disabilities to live independently and be included in the community.**

Inclusion Europe strongly advocates for the right to choose, and for it to be encouraged. We also advocate for self-determination of people with disabilities. However, as underlined by Paragraph 25, various factors can influence and impair the choice made by a person such as:

- lack of information given to people living in institution,
- lack of adequate options,

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- lack of experience with living independently in the community,
- long-term institutionalisation,
- lack of support during the deinstitutionalisation process,
- lack of peer support,
- legislative barriers,
- and stigma.

We think this paragraph fails to tackle the main issue at stake: the expression of a free and informed choice supported by realistic choices and without barriers.

Because of the danger implied by this paragraph and its internal contradiction, Inclusion Europe proposes to remove paragraph 47.

13. Paragraph 50 and 53

Inclusion Europe regrets that the draft GC does not highlight the crucial and positive role played by families across the world. In many countries, they are the sole support that persons with intellectual disabilities can rely on.

Families cannot be merely assimilated to third parties (paragraph 51) and should not be seen as a rigid category in itself.

Families are encompassing an infinity of members, such as parents, brothers, sisters, grandparents, godparents, aunts, or uncles which all may have important and distinct roles in supporting the realisation of an inclusive and independent life for their relative with a disability.

Families are especially important during the main transition periods in life – in childhood (such as starting school, adolescence etc.) and from childhood to adulthood (such as going to university, finding employment, starting a family etc.). Families are essential in helping their members develop independent living skills, facilitating their development and social inclusion.

We are concerned that families are mainly mentioned in the part on the obligation of Member States to protect against third parties (paragraph 53). While we recognise that overprotection and abuse also can take place in family environment, this has to be interpreted in the context of the lack of adequate support for people with disabilities.

Many families who are very isolated and with no support can also identify institutions as the only “safe” choice for their relative.

The current wording of the draft GC may be interpreted in a negative way towards families, enhancing some of the prejudices and discrimination they are subjected to. Instead, we would suggest a stronger focus in the draft GC on the obligation of States Parties to provide family carers with adequate support.

Change to paragraph 50

The obligation to protect requires States parties to take measures to prevent family members and third parties from directly or indirectly interfering with the enjoyment of the right to independent and community living. The duty to protect requires States parties to put in place and implement laws and policies prohibiting conduct by family members and third parties, such as ~~families~~, service-providers, landlords or providers of general community services, which undermines the full enjoyment of the right. It includes the prohibition of all forms of guardianship as well as the transition from substitute decision-making to supported decision-making. 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.

Change to paragraph 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~~ Many family members 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 of persons with disabilities by members of the family, as well as~~ State parties should 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.

14. Paragraph 55

Inclusion Europe is really attached to the holistic approach given by the draft GC to independent living and thinks that it requires a participation of all in the transitional process. Disabled people's organisations as well as family organisations should be consulted at each step of the deinstitutionalisation process: preparation and adoption of a strategy, implementation, assessment.

Change to Paragraph 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 as well as the ones of families 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.

15. Paragraph 56

Inclusion Europe would like to highlight the obligation of State Parties through a stronger terminology in the targeted paragraph.

Change to Paragraph 56

States parties ~~should~~ have to adopt a strategy for deinstitutionalization. Deinstitutionalization 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.

Additional comments

16. Social and psychological support

Inclusion Europe would like to highlight that while working on preparing the transition from institutionalised to community-based service models, States parties must focus on the support needs of the people with disabilities concerned. A previous live in an institution is likely to leave people victimised by experiences of violence, abuse or by the experience of non-recognition of their will and preferences. Thus, it is not enough to move people physically from one service to another, but the necessary trauma support needs to be provided as well. So does the necessary support for inclusion in the community.

Addition of a paragraph 28 (bis) in D. Article 19 (b)

Persons who have lived in institutional settings for a long time are also likely to have experienced a disregard for their will and preferences, in many cases also violence and abuse. Persons with disabilities making the transition from institutions to independent and community living may thus need specific support to facilitate their coping with these experiences and support their inclusion in society to enable them to live an active and independent life in the community.

17. Inclusive monitoring process of community based services

Inclusion Europe is concerned by the “re-institutionalisation” that has occurred in some countries where recently developed community based services have been replaced again by institutions. This can constitute a real challenge to deinstitutionalisation in a long-term perspective.

The General Comment should acknowledge this risk and raise the importance of the assessment by people with disabilities and their families of newly created services.

A paragraph should be added to talk about the assessment of the newly created community-based services and the prevention of “re-institutionalisation” in D. Article 19 (b).

18. Preventive and transitional aspects of deinstitutionalisation

Inclusion Europe insists on the importance of both preventive and transitional aspects of the deinstitutionalisation process. While the focus is often on the transition from institutional to community based care, **it is crucial to prevent people from being institutionalised in the first place.**

People have to be supported and accompanied to develop independent living skills during their life to the fullest possible extent. The development of support services responsive to people’s needs, (re)training of professional providing services, awareness-raising and capacity-building of family members and other relevant actors of deinstitutionalisation in the community.

A paragraph should be added regarding the two aspects of deinstitutionalisation and what it should imply in D. Article 19(b).

19. Support families

Inclusion Europe applauds the recognition that families do not replace the obligations of State parties in the exercise of the right to live independently and being included in the community. However, this acknowledgement is not followed by concrete recommendations for States to support families which are, in many countries, the sole support for people with intellectual disabilities. While we do recognise the importance of awareness-raising and capacity-building, we think that the General Comment should also address the provision of support to families including short term “respite” care services, circles of support, counselling and other relevant support.³

Addition of a paragraph in “C. Obligation to fulfil” (p.13)

‘States parties should provide adequate support to family members, so that they can support their child or relative to live independently. The role of the families is critical during the transition periods in childhood and adulthood. Family support includes short term “respite” care services, childcare services and other parenting support services. Financial support is also crucial for families with members with disabilities who often live in situations of poverty,

³ Several examples have been described by Inclusion Europe in previous study. See Inclusion Europe, The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, Volume 4: Examples of Good Practice.

without the possibility of accessing the labour market. States parties should provide social support to families and foster the development of counselling services, circles of support and other adequate support options.'

20. Children with disabilities and obligation of States

Inclusion Europe wishes to raise the situation of children who are institutionalised and the corresponding duties of State parties to prevent this. We support the holistic interpretation of article 19 by the draft GC and propose to target early intervention in more practical terms than in the introductory paragraph.

Addition of a paragraph in "C. Obligation to fulfil" *State parties*
must take positive actions to prevent children with disabilities from being separated from their families. They should enjoy, on equal basis with other children, the right to grow in a familial environment. It entails an obligation for the States to reform the educational system towards an inclusive model and to enable children to attend schools near their family place. This duty cannot be fulfilled without an adequate support provided to both children and families.

21. Self-advocacy

Inclusion Europe welcomes the importance given to individualised support, but regrets a quasi-absence of community support issues in its analysis. Peer support, circles of support and the essential role of self-advocacy organisations in empowering people with disabilities, including people with complex support needs, to make their own decisions and to live independently cannot be overlooked in the realisation of this right. It is essential to give self-advocates more control of the deinstitutionalisation process by systematic consultations with policy-makers and service providers in deinstitutionalisation strategies.

Addition of a paragraph in "C. Obligation to fulfil" (p.13)

Organisations of self-advocates have an essential role to play in providing expertise and advice on the implementation of the right to live independently and being included in the community. This importance should be formally recognised by States parties through the allocation of funds to their organisations as well as their full participation in the development, implementation and assessment of legislation and policies. State parties have also a role to play in raising the awareness of people with disabilities about their rights, including people living in institutional care settings.

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