



THE RIGHT TO LIVE INDEPENDENTLY AND BE INCLUDED IN THE COMMUNITY

Addressing Barriers
to Independent Living
across the Globe



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Table of Contents

Acknowledgements	1
Executive Summary	5
I. Introduction	7
1.1 Scope and purpose of this report.....	7
1.2 Article 19 of the Convention on the Rights of Persons with Disabilities: Overview	7
1.2.1 Article 19 of the CRPD: promoting inclusion and participation	8
1.2.2 Article 19: Independent living and inclusion in the community	9
1.3 Research methodology	10
II. Barriers to the realisation of Article 19	11
Chapter 1: Misunderstanding and misuse of key terms	11
1.1 Misconceptions related to Article 19 terminology	11
1.2 Misconceptions related to culture	14
1.3 Lost in translation	16
1.4 ‘Hijacking’ of the CRPD language	16
Recommendations	17
Chapter 2: Negative attitudes and stigma	18
2.1 Influence of tradition and religion.....	19
2.2 Medicalisation of disability	20
2.3 Individualism	20
Recommendations	20
Chapter 3: Lack of support to the family	21
3.1 The importance of family support.....	21
3.2 Problems caused by the lack of support to the family	21
Recommendations	22
Chapter 4: Prevalence of institutional services.....	23
4.1 Traditional institutional care	23
4.2 Contemporary institutions	25
4.3 Non-residential institutions.....	28
4.4 Institutionalisation in the community and at home.....	28
4.5 Re-institutionalisation – when deinstitutionalisation goes wrong	28
Recommendations	30
Chapter 5: Barriers related to community support services	31
5.1 Availability, accessibility and affordability of support	31
5.2 Restricted access to services	34
Recommendations	37
5.3 Poor quality services	38
Recommendations	38

5.4 Inadequate resources.....	38
Recommendations	40
Chapter 6: Barriers in Mainstream Services and Facilities	41
Recommendations	42
Chapter 7: Barriers to other CRPD rights that impact on independent living.....	43
7.1 Poverty and disability-specific costs.....	43
7.2 Substitute decision-making.....	44
7.3 Cross-cutting issues	44
7.4 Lack of equal access to education and employment.....	45
7.5 Participation	46
7.6 Lack of data	46
Recommendations	47
 Conclusion	 49
Annex 1 – Independent Living Definitions	50
Annex 2 – Frequently asked questions	51

Executive Summary

This report looks at the main barriers to the realisation of disabled people's right to live independently and be included in the community, which is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). They are grouped in seven broad areas: (1) misunderstanding and misuse of key terms, (2) negative attitudes and stigma, (3) lack of support for families, (4) prevalence of institutional services, (5) barriers related to community support services, (6) barriers in mainstream services and facilities, and (7) barriers, concerning other CRPD provisions, with effect on Article 19. A set of recommendations is also provided, outlining measures required to address these barriers.

The recommendations in this report – presented below – were shared with the UN Committee on the Rights of Persons with Disabilities when they were drafting the General Comment on Article 19. They can be used by governments and civil society organisations, alongside the General Comment, to identify actions needed to implement Article 19¹ CRPD.

- **Ensure common understanding of the key terms:** It is essential to ensure that stakeholders' understanding of Article 19 and key terms (such as, independent living, personal assistance, community support services, and de-institutionalisation) is in line with the philosophy and the principles of the CRPD, set out in Article 3. This means recognising that disabled people are recognised as having the same opportunities for choice and control over their lives as non-disabled people; and that *all* disabled people, regardless of their support needs, gender, or age can live independent lives and participate in the community. It also means acknowledging that Article 19 reflects cultural diversity – States Parties to the CRPD ('States') are required to develop a range of support services in the community, but this does not have to reflect a particular, 'western', model. States can decide what services to develop, provided that they respect the principles of choice and control by disabled people and non-segregation from the community.
- **Adopt a comprehensive deinstitutionalisation strategy:** Where institutions exist, a comprehensive deinstitutionalisation strategy should be adopted with a reasonable timeframe, clear benchmarks and adequate budget. It should recognise independent living and full inclusion in society as a right for all disabled people. It should include measures in three key areas: (1) closure of residential institutions for disabled people², (2) development of support in the community and (3) making mainstream services and facilities accessible. Funds from institutions should be set aside and redirected to support services for disabled people in the community.
- **Develop support services in the community:** A range of affordable, quality, culturally appropriate community support services should be developed for disabled people and their families. They should respect disabled people's dignity and autonomy and aim to facilitate their full inclusion and participation in society. Access to services should not be limited by characteristics such as age, gender, support needs, family situation, place of residence, or requirements related to disabled people's engagement in education or employment, or acceptance of medical treatment.

States should ensure that there are adequate resources for the development of support in the community. Limited resources do not relieve States from the obligation to strive to ensure the widest possible enjoyment of the right to independent living and inclusion – they should take steps towards the realisation of this right, including by establishing strategies and programmes with clear benchmarks and time frames. States should also refrain from introducing retrogressive measures such as cuts in services and benefits, and restrictions of access to services. Where such measures have already been introduced, the States should analyse their impact on the rights of disabled people and take remedial actions.

1 Draft General comment No. 5 (2017), available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticle19.aspx>.

2 For a definition of 'institution', see section Prevalence of institutional services on p. 23.

- **Make mainstream services and facilities accessible to all:** Measures to make mainstream services accessible to persons with disabilities should be implemented in parallel with measures to develop support services in community. It should also be ensured that mainstream policies, programmes and projects take into account the needs of disabled people. For example, infrastructure projects, such as the reconstruction or building of a railway station or a school, should incorporate accessibility standards; a training for professionals should include topics related to disabled people and human rights.
- **Carry out awareness raising activities:** Awareness raising activities should be implemented to address negative stereotypes and discrimination against disabled people. They should promote a human rights understanding of disability and should be aimed at professionals (for example, social workers, medical doctors, teachers), media, family and community, and disabled people.
- **Ensure access to social protection:** Access of disabled people to social protection programmes and services should be ensured. They should receive support with disability-related extra costs and should have access to public housing programmes, retirement programmes, and appropriate and affordable services, devices or other disability-related assistance.
- **Recognise the right to legal capacity:** The right to legal capacity of disabled people should be legally recognised. In addition, all forms of substitute decision-making should be abolished and replaced by supported decision-making arrangements, recognizing disabled people's right to make their own decisions.
- **Address multiple discrimination:** Special attention should be paid to planning and implementing measures to address additional barriers disabled people face, due to their belonging to one or more social group. For example, barriers related to the person's race, ethnicity, gender identity, sexual orientation, religion, language, social status, and other characteristics.
- **Involve disabled people and their organisations:** Disabled people and their organisations should be involved in all decisions affecting them. This includes, for example, involvement in developing national, regional and local legislation and policies, reviewing the implementation of policies and programmes, and assessing quality of services. They should also be involved in the independent mechanism established by the States, in line with Article 33, to monitor the implementation of the Convention.

Mechanisms should be established to ensure that involvement is systematic, rather than ad hoc. Measures should also be taken to ensure that disabled people can participate meaningfully, by taking into account their accessibility requirements.

- **Collect data:** Disaggregated data should be collected by States, to allow for monitoring of progress towards the right to independent living.

I. Introduction

1.1 Scope and purpose of this report

This report concerns the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which recognizes the right of disabled people³ to live independently and be included in the community. Based on research conducted by the European Network on Independent Living (ENIL), the report explains the importance of Article 19, outlines the key barriers to realising this right and makes recommendations on how to address such barriers and facilitate its effective implementation.

By highlighting the importance of Article 19 and identifying the action needed to realise this right, this report aims to be of assistance to governments and civil society organisations, seeking to establish what action is required to achieve disabled people's full inclusion and participation in society. An earlier draft of the report was shared with the Committee on the Rights of Persons with Disabilities ('the CRPD Committee')⁴ during the drafting of the General Comment on Article 19. The report can be used alongside the General Comment, once it is adopted by the Committee.

Of key concern is that, in addition to economic and political factors, the realisation of Article 19 is hindered by the lack of understanding of human rights principles, the concept of independent living and what is required to ensure the full inclusion and participation of disabled people. As a result, progress is slow and sometimes one form of exclusion is dismantled, only to be replaced by another (for example, contemporary institutions⁵). The lack of understanding of the links between the articles of the Convention is also a barrier to the realisation of Article 19. For example, the lack of equal recognition before the law (Article 12) restricts the right of many disabled people to choose where they live and can lead to institutionalisation, against their will.

This chapter begins with an overview of Article 19 of the CRPD and why it is so important, and goes on to explain the research methodology. This is followed by an outline of the subsequent chapters, which discuss the barriers to independent living identified through the research.

1.2 Article 19 of the Convention on the Rights of Persons with Disabilities: Overview

The CRPD was adopted in 2006 and came into force on 3rd May 2008. The Convention covers both civil and political rights (such as the promotion of equality and protection from discrimination, the right to freedom from exploitation, violence and abuse, and participation in political and public life) and economic, social and cultural rights (such as the right to education, work and adequate standard of living). In the context of disability, economic, social and cultural rights are especially important, as they make it possible for disabled people to exercise their civil and political rights. They enable them to live independently and to participate in their communities, forging 'pathways into inclusive societies and economies'.⁶ The CRPD is also the first human rights treaty that recognizes the right of disabled people to live in the community as equal citizens.

3 The report uses the term 'disabled people', rather than 'persons with disabilities' or 'people with disabilities', to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability.

4 The body responsible for monitoring States' implementation of the CRPD.

5 See section Contemporary institutions on p. 25.

6 Quinn, G. (2009) 'A short Guide to the United Nations Convention on the Rights of Persons with Disabilities', in Quinn, G and Waddington, L. (eds) *European Yearbook on Disability Law*, Oxford: Intersentia, p.92-93.

The Convention embodies a ‘social model of disability’, which underlines the role of attitudinal and environmental barriers in hindering disabled people’s full and effective participation in society on an equal basis with others. Accordingly, the CRPD represents a paradigm shift in the way disability is viewed – ‘from the treatment of persons with disabilities as “objects” of charity, medical treatment and social protection, towards viewing persons with disabilities as “subjects” with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society’.⁷

In contrast, the history of disabled people across the world has been one of segregation, isolation and exclusion from society. Locked in institutions or in their homes, banned, by laws or culture, from going out and taking part in the political and social life, disabled people became increasingly invisible to the society. It is for this reason that Article 19 is so important.

1.2.1 Article 19 of the CRPD: promoting inclusion and participation

Article 19 of the CRPD and the themes of inclusion and participation that run throughout the CRPD seek to address the exclusion of disabled people. Article 19 recognizes the right of disabled people to live independently and be included in the community. This is underpinned by one of the general principles of the CRPD set out in Article 3, namely, the ‘full and effective participation and inclusion in society’.⁸

Article 19 sets out the right of all disabled people ‘to live in the community, with choices equal to others’, requiring that States Parties to the CRPD (‘States’) ‘take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community’. In meeting their obligations under Article 19, States are required to take a range of actions. Three specific areas are identified as requiring attention. Thus, States must ensure that disabled people have a choice of residence on an equal basis with others; access to support in the community; and access to mainstream services and facilities.

Article 19 – Living Independently and being Included in the Community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a)** Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b)** Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c)** Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

⁷ See UN Enable, ‘Paradigm shift’, available at: <http://www.un.org/esa/socdev/enable/convinfopara.htm>

⁸ CRPD, Article 3(c).

1.2.2 Article 19: Independent living and inclusion in the community

Although various definitions of independent living have been developed by disabled people and their organisations,⁹ they encompass two common elements. The first is the understanding of independent living as being able to make decisions about one's life. This includes simple decisions, such as when to go out and what to eat, as well as big and important ones, such as where and with whom to live or whether to have children. The second is the link to inclusion in the community, which requires the provision of services and support to enable disabled people to participate in the community.

i) Choice and control

Independent living requires that disabled people have the same opportunities for choice and control over their lives as non-disabled people.

While the CRPD does not include a specific definition of 'independent living', the common understanding of independent living as having choice and control is reflected in Article 19 and is one of the key principles of the CRPD. Article 19(a) requires that disabled people have the opportunity to make decisions about where and with whom they live on an equal basis with others. Article 3(a) of the CRPD requires '[r]espect for inherent dignity, individual autonomy, including the freedom to make own choices, and independence of persons'.

ii) Inclusion and access to services and support

Many of the definitions of independent living link this concept to the right to be fully included in the community.



'Independent living is living within my community and being able to access services within my community on an equal basis as others. And also, being able to have choices and autonomy within my community, the same as other people who are living within that particular community.'¹⁰



'The term 'community living' (also known as 'independent living') refers to: ...people with disabilities being able to live in their communities as equal citizens, with the support that they need to participate in everyday life, such as living in their own homes with their families, going to work, going to school and taking part in community activities.'¹¹

The essential precondition for the full enjoyment by disabled people of their right to live independently and be included in the community is the availability and accessibility of support and mainstream services and facilities¹². The definition of independent living, adopted by ENIL and the European Disability Forum (EDF), explicitly underlines this aspect.



'Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to

9 See, for example, <http://enil.eu/news/european-disability-movement-agrees-definition-of-independent-living/> and <http://www.independentliving.org/indexen.html>

10 Consultation Africa.

11 Parker, C. (2009) 'An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities', in Focus Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities. London: European Coalition for Community Living, p. 21, available at: <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf>

12 See Article 19, (b) and (c).

live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.¹³

Article 19 requires the States to take action to ensure that disabled people are able to live and participate in the community ‘with choices equal to others’. This involves disabled people being able to study in their local school, use public transport to go to work, have a family and take part in community activities.

1.3 Research methodology

The research undertaken for this report was conducted by the European Network on Independent Living (ENIL), during October 2016 – January 2017. It involved a literature review and consultations with disabled people, their families and other stakeholders from Africa, Asia and the Pacific, Europe, Latin America, Middle East and North Africa, and North America. The consultations took the form of interviews, written contributions or presentations at events, organised by ENIL. Those consulted represent different groups of disabled people, in terms of gender, age and type of impairment.

The research considered the following key questions:

- What are the barriers to the realisation of the right to live independently and be included in the community?
- How is the term ‘independent living’ understood? How does culture affect that understanding?
- How can the barriers to the realisation of Article 19 be addressed?
- How can the General Comment on Article 19 support the realisation of the right to independent living?

Quotes from individuals who took part in the consultation are included throughout the report and are presented in shaded boxes.

13 See Annex 1 for all ENIL independent living definitions.

II. Barriers to the realisation of Article 19

This part of the report considers the range of barriers that restrict disabled people's choice and control and hinder their participation in the community. It consists of seven chapters:

Chapter 1: Misunderstanding and misuse of key terms

Chapter 2: Negative attitudes and stigma

Chapter 3: Lack of support to the family

Chapter 4: Prevalence of institutional services

Chapter 5: Barriers related to community support services

Chapter 6: Barriers in mainstream services and facilities

Chapter 7: Barriers to other CRPD rights that impact on independent living

Chapter 1: Misunderstanding and misuse of key terms

Misconceptions and misuse of independent living and inclusion terminology is a serious barrier to the implementation of Article 19. It can lead to inconsistencies and replication of exclusionary policies and practices under the guise of independent living. It is also a challenge for the disability movement, as it can lead to rejection of the notion of 'independent living'. Many disabled people, who cannot do everything on their own or do not want to live alone, as the misconception about independent living demands, reject the notion of 'independent living'. This jeopardizes the work of disabled people's movement and weakens the demands for genuine independent living policies.

Misconceptions about key terms, related to Article 19, are widespread in all parts of the world and among various stakeholders.¹⁴ Terms such as 'independent living' or 'support in the community' are often understood and used incorrectly by policy makers and service providers, but in some cases, they are also misunderstood by disabled people and their families.

1.1 Misconceptions related to Article 19 terminology

This section looks at misconceptions related to some of the key Article 19 terms, such as 'living independently' (or 'independent living'), 'community support services', 'personal assistance' and 'deinstitutionalisation'. Deinstitutionalisation, although not explicitly mentioned in Article 19, is included here, because it is of crucial importance for disabled people's inclusion and independent living. This is also recognised by the CRPD Committee, which has made recommendations to the States to take action towards deinstitutionalisation in many of its Concluding Observations.¹⁵

¹⁴ For a collection of independent living myths, see ENIL (2014) 'Myth buster on independent living', available at: <http://enil.eu/news/the-enil-myth-buster-now-available-in-6-languages/>.

¹⁵ See, for example, the CRPD Committee Concluding Observations on Argentina, Austria, Azerbaijan, Belgium, Bolivia, Colombia, Costa Rica, Croatia, Czech Republic, Ecuador, El Salvador, European Union, Guatemala, Hungary, Lithuania, Mauritius, Mexico, Paraguay, Republic of Korea, Serbia, Slovakia, Thailand, Turkmenistan, Uganda and Ukraine, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5.

Independent living

As noted in the Introduction, two core features of independent living are a) choice and control and b) access to support in community and to mainstream services. However, this term is often wrongly used to mean living away from your home; living on your own; and doing things for yourself, managing without support from family, community or services.



‘Many disabled people get confused and think ‘If I have my independence, I can do everything myself, I do not need you.’¹⁶



‘The majority of the people – disabled people, their families, politicians and media – think that independent living means doing things for yourself, on your own.’¹⁷

It is important to stress that ‘independent living’, as understood by the CRPD:

- **Does not require leaving one’s family and community.** For some people, it may mean moving away from their family, for others – it may mean living with their family. The key issue is that it must be the disabled person who makes the decision and this must be the person’s genuine choice; that is, the person’s choice is not restricted by environmental and attitudinal barriers and/or the lack of support.
- **Does not mean being self-sufficient.** There is no conflict between independence and interdependence. On the contrary, the CRPD sees independence as related to interdependence.¹⁸ Thus, independent living requires disabled people to have ‘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’.¹⁹
- **Does not mean living without support from the state,** but having enough state support to enable inclusion. Choice and control over the support is an essential precondition for independent living.
- **Does not require putting disabled people in a more privileged position** and does not involve giving more protection to disabled people than to other members of the community. It is about disabled people **having the same choices** as non-disabled people.

Finally, independent living is **for all disabled people**, regardless of their support needs, gender, age or the place they live (in an institution or at home).

Community support services

‘Community support services’ are services, based in the community, that support ‘living and inclusion in the community’ and ‘prevent isolation and segregation from the community’.²⁰ However, this term is commonly used incorrectly to refer to services that are physically located in the community, but are not necessarily inclusive; for example, group homes, sheltered workshops, and day-care centres. Often, such services perpetuate segregation and exclusion from the community, because they maintain a parallel system for disabled people, away from the mainstream.²¹

¹⁶ Consultation Asia and the Pacific.

¹⁷ Consultation Europe.

¹⁸ OHCHR (2012) ‘Getting a life – living independently and being included in the community. Office of the United Nations High Commissioner for Human Rights, regional Office for Europe, p. 12.

¹⁹ OHCHR (2014) *Thematic study on the right of persons with disabilities to live independently and be included in the community*, Office of the United Nations High Commissioner for Human Rights, para. 13, available at: http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Documents/A_HRC_28_37_ENG.doc

²⁰ Article 19(b).

²¹ For more details, see the section Contemporary institutions on p. 25.

Whether a service is ‘community-based’ should be determined by its contribution to independent living and inclusion, rather than simply by its location in a community. Location, although important, is not a sufficient criterion.

Personal assistance

The term ‘personal assistance’ refers to individualised support for disabled people, which enables them to overcome environmental barriers and to live independently. A key characteristic of genuine personal assistance is that disabled people have maximum choice and control over their support. This requires:

- disabled people being able to choose their own assistant, and to decide how, where and what support is provided to them²²;
- provision based on individual needs and life situation (that is, each disabled person is provided with the adequate number of hours);
- access to personal assistance for all disabled people, regardless of their impairment or age. In the case of children, personal assistance does not seek to replace parental care but to complement it, supporting independent living;
- adequate support to people wishing to manage their assistance, including support to people with intellectual and psychosocial disabilities, enabling them to participate in decisions about how support is provided.²³

However, ‘personal assistance’ is often incorrectly applied to a variety of assistance schemes that do not give disabled people choice over how, when, where and by whom the assistance is provided, or limit the tasks that a personal assistant can do.²⁴ The access of certain groups of disabled people, for example, people with intellectual or psychosocial disabilities, or children, is also often restricted.²⁵

Deinstitutionalisation

‘Deinstitutionalisation’ is a means to achieving the goal of independent living and inclusion in the community for all disabled people, regardless of their support needs, gender or age. It involves: 1) the closure of institutions, 2) a moratorium on the building of new institutions, 3) ensuring access to support in the community and mainstream services and 4) putting in place measures to prevent institutionalisation in the future.²⁶ All four elements need to be in place to ensure disabled people’s inclusion.

However, this term is wrongly used as synonymous with transforming large residential institutions into contemporary institutions, or closing large institutions without putting in place alternatives, rather than ensuring equal access to services and support in community. While the closure of large residential institutions is essential, it is not sufficient to ensure that disabled people can live independently and be included in the community. Without support in the community and accessible and affordable mainstream services – including housing - disabled people leaving institutions will not be able to participate in society on an equal basis with others.

22 On personal assistance requirements see ENIL Submission for the Day of General Discussion on the right of persons with disabilities to live independently and be included in the community, available at: www.enil.eu. See also Ratzka, A. (2004) *Model national personal assistance policy*, available at: <http://www.independentliving.org/docs6/ratzka200410a.html#6>.

23 See ENIL (2013) Fact sheet: Independent Living, available at: <http://www.enil.eu/policy/faq/>.

24 Jolly, D. (2009) *Personal Assistance and Independent Living: Article 19 of the UN Convention on the Rights of Persons with Disabilities*. ENIL Position Paper. Available at: www.enil.eu/wp-content/uploads/2014/05/FAQ_Personal_Assistance.pdf. See also ENIL (2013) Fact Sheet: Personal assistance, available at: http://enil.eu/wp-content/uploads/2014/05/FAQ_Personal_Assistance.pdf.

25 See ENIL’s survey on personal assistance services in Europe, available at: <http://enil.eu/policy/personal-assistance-tables/?s=personal+assistance+survey#>.

26 See ENIL definition of ‘de-institutionalisation’ in Annex 1. See also the recommendations in Chapter Prevalence of institutional services.

1.2 Misconceptions related to culture

Concerns have been raised about the universal applicability of the independent living concept. It is often seen as a 'western' concept, promoting an individualistic and atomistic view of people. As such, it is thought to be incompatible with the communal cultures of some indigenous peoples and countries in Africa, Asia and the Pacific and Latin America, where mutual caring and support in the community is a norm and people continue to live with their families into adulthood. Furthermore, formal services can sometimes be seen as a threat to local culture and family relationships, which is a serious barrier to the introduction of independent living policies. According to Takamine, an academic from Asia:

“Independent living carries with it the tone of individualism that is one of the major characteristics of the Western culture. In some instances, independent living means to break away from family members to become financially and emotionally independent of their influence. It requires a certain degree of assertiveness to express one's clear opinion or choice. In the Western culture, children are expected to leave their home and become independent of their parents when they reach a certain age, including persons with disabilities. Thus, it is natural for disabled persons to try to seek an independent lifestyle.... People in this region [Asia and the Pacific], however, tend to adhere to harmonious existence rather than confrontational. They are more concerned about group conformity imposed by the family, peers, clan and the community they live in.’²⁷

These points were echoed by participants in the consultation for this report:

“...Family is an important issue to us. So, to get to live independently in adulthood is not an important issue as it might be in North America or maybe in Europe or in other parts of the world... Our cultural issues push us... to raise our child in our homes or the families. We are used to live with our son or daughter with disabilities even if they become adult.’²⁸

“...[in Africa] we have a very communal way of living...just because many people in Africa live with their community, in their community, with their families and relatives, then people tend to assume that they are not able to live independently.’²⁹

“Certain cultures here [of indigenous populations] ...they tend to look to extended families for support and, as a result, the concept of 'independence' is a bit hard for them to understand.’³⁰

“...suppose I have all kinds of services provided by the state and I am living alone in my house and I have this assistance with everything, will it make my family redundant? It is just me and all my services.’³¹

Such concerns arise from a misunderstanding of Article 19 and can be addressed by ensuring that the philosophy of Article 19 is well understood. Article 19 does take into account cultural differences, requiring disabled people to have the same choices *other people in their community have* in all areas

27 Takamine, Y. (1998) 'The cultural perspectives of independent living and self-help movement of people with disabilities', *Asia and the Pacific Journal on Disability* 1(2). Available at: <http://www.dinf.ne.jp/doc/english/asia/resource/z00ap/002/z00ap00208.html>

28 Consultation, Latin America.

29 Consultation Africa.

30 Consultation Asia and the Pacific.

31 Consultation Asia and the Pacific.

of life ('choices equal to others'). It requires the States to develop a range of support services in the community, without limiting them to a particular, 'western', model. Thus, States can develop a variety of support services that are culturally appropriate for their specific communities, including adapted to indigenous, minority and rural practices. The only requirements are to ensure that services 'support living and inclusion in the community', 'prevent isolation or segregation from the community'³² and respect disabled people's 'individual autonomy, including the freedom to make one's own choices, and independence of persons'.³³

“Article 19 reflects the diversity of cultural approaches discussed during the negotiations of the Convention on the Rights of Persons with Disabilities, where care was taken to ensure that the right covered under the article was not limited to the provision of services available in developed countries. States parties are given a range of options, with the provision that they respect the principles of control by persons with disabilities over their lives and non-segregation from the community.”³⁴

The view of independent living as culturally specific is not based on the understanding of independence as choice and control, which is promoted by the Convention. There are, of course, cultural differences with regard to how choice and control is exercised – with more or less involvement from the family and the community, focusing on the individual or family interests. However, it remains a problem in most cultures, individualistic or communal, that disabled people's opinion and preferences are not valued and are often not taken into account in decision-making. While no one has full control over their lives, disabled people have less control than most people, due to the additional environmental and attitudinal barriers they face.

Some of the participants in the research addressed the common misunderstandings about 'independent living' and stressed the universality of the concept.

“Independent living doesn't mean that we live away from our community..., especially in the rural areas...it is about yes, I depend on my family, yes I depend on my natural informal support within my community, but I am able to access services within the community, I am able to have autonomy and control, within the community, over my life [...] I live alone, but that does not mean that I do not depend on my sister or my mother for support in a lot of areas in my life [...] It's not about living in isolation. It is about me, having my own autonomy and yet, being able to access natural forms of support and to live actively within my community.”³⁵

“...humans will always need other humans. And that's for everybody, you know, people with or without disabilities. We always need somebody'...This is interdependence'...I don't think anybody can be truly independent, because we have somebody in our lives.”³⁶

32 Article 19 (b).

33 Article 3 (a).

34 OHCHR (n. 18), para. 12.

35 Consultation Africa.

36 Consultation Asia and the Pacific.

1.3 Lost in translation

Often, misconceptions about independent living are reflected in the different translations of the Convention. For example, ‘living independently’ is translated in Bulgarian and Russian as ‘self-sufficient’ (samostoyatelen zhivot – in Bulgarian, and samostoyatel’nyi obraz zhizni – in Russian), and as ‘autonomy of living’ in French (autonomie de vie).³⁷ The German translation of the Convention uses ‘integration’ instead of ‘inclusion’, thus failing to distinguish between a focus on removing barriers in society (inclusion) and a focus on making individuals fit into the existing system.³⁸

1.4 ‘Hijacking’ of the CRPD language

The language of the CRPD is important, as it promotes a certain view of disabled people, based on human rights and equality. However, the experience with the implementation of the Convention so far shows that different groups try to bend the meaning of key terms to fit their interests.³⁹ ‘Hijacking’ of terminology thus refers to different actors altering the meaning of key terms, promoted by the CRPD and disabled people’s movement, and using them to justify certain policies and practices, often contrary to the CRPD values and goals. For example, a strong critique was voiced recently by Mark Oliver, one of the key figures in the European disability movement, against the abuse of the term ‘independent living’ by policy-makers. He noted that the individualistic view of independent living as self-reliance and self-sufficiency, promoted by the British government, is used to justify the withdrawal of state support.



‘...they [the government] can claim they are giving us what we have asked for: independent living.... The problem is that they don’t mean giving us the support to enable us to exercise our autonomy and self-determination, but to be independent from them and the state.’⁴⁰

Similar tendencies have also been observed outside Europe, by Yang:



‘From the government’s perspective, starting IL [independent living] implies more individual responsibility for disabled people in welfare provision. The government support is meant to facilitate independence from the state rather than to enhance the rights consciousness of disabled people.’⁴¹

Terms can also be hijacked by other actors, such as service providers, who could have vested interests, for example, in preserving the status quo. Thus, one of the participants in the consultations shared that the term ‘community-based services’ is used to justify the provision of the existing system of segregating services – ‘[s]ome service providers say that actually an institution ... is included within a spectrum of community-based services.’⁴²

37 See Mladenov, T. (2013) ‘The UN Convention on the Rights of Persons with Disabilities and its interpretations’, in *ALTER – European Journal of Disability Research* 7(1): 69–82, available at: <http://www.sciencedirect.com/science/article/pii/S1875067212001009>

38 BRK – Allianz (2013) *For independent living, equal rights, accessibility and inclusion!* First civil society report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Germany, available at: http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DEU/INT_CRPD_NGO_DEU_16323_E.doc, p.9

39 See also Mladenov (n. 36) and Quinn, G. (2009) ‘Resisting the “temptation of elegance”: Can the Convention on the rights of persons with disabilities socialise states to right behaviour?’ In O. M. Arnardóttir, & G. Quinn (Eds.), *The UN Convention on the rights of persons with disabilities: European and Scandinavian perspectives*, pp. 215–256. Leiden and Boston: Martinus Nijhoff Publishers

40 Oliver, M. (2013), quoted in Pring J. (2013) ‘Oliver warns of fakes and false friends’, in first speech for 10 years. *Disability News Service*. Available at: <http://www.disabilitynewsservice.com/oliver-warns-of-fakes-and-false-friends-in-first-speech-for-10-years/>.

41 Yang, C. (2013) ‘Being independent from whom? Analysing two interpretations in the paradigm of ‘independent living’, *Disability and Society*, 29(5), p. 681.

42 Interview, Asia and the Pacific.

The ‘hijacking’ of the language of Article 19 is a major hindrance to the implementation of the Convention. It could be challenged by a strong international or regional monitoring mechanism, and national monitoring bodies that fully understand the philosophy of the Convention. Active involvement and actions on the part of disabled people and their organisations are also essential for ensuring that the CRPD is adequately translated into the national, regional and local legislation and policies.

Recommendations⁴³

- ▶ It is important to ensure that the key stakeholders, including disabled people and their families, policy-makers, non-governmental organisations, and relevant professionals, have a good understanding of key Article 19 terms, in line with the values and principles of the Convention. This means recognising that disabled people are entitled to the same opportunities for choice and control over their lives as non-disabled people.
- ▶ It is important to acknowledge that there can be a variety of culturally appropriate measures to support independent living, as long they provide disabled people with choice and control over their support.
- ▶ To ensure that legislation and policy are based on the CRPD principles, all the relevant legislation and policy should be reviewed by the CRPD monitoring mechanisms⁴⁴, before they are officially adopted. For example, when drafting legislation, the Government should consult with the CRPD monitoring body to ensure it is CRPD compliant.

43 The recommendations in this section are mostly focused on definitions. Measures to support independent living are discussed in more detail in the following sections.

44 See CRPD, Article 33 (2).

Chapter 2: Negative attitudes and stigma

In all parts of the world, negative attitudes, stereotypes and stigma are a serious hindrance to the development and implementation of inclusive policies, even when there is political will for reforms. They can lead to explicit or implicit opposition from key stakeholders – professionals, communities, families, even disabled people themselves, many of whom may have internalised these attitudes. For example, communities can be unwilling to accept disabled people and protest against the opening of residential facilities⁴⁵, parents might oppose having a disabled child in their child's class⁴⁶, professionals can limit the choices of certain groups of disabled people, because of their perceived lack of capacity to make choices for themselves. Disabled people may be unwilling to leave an institution, because they find it difficult to imagine a life outside.⁴⁷

Negative attitudes and stereotypes can also be internalised by disabled people, influencing their self-perception and behaviour, preventing them from claiming their rights:



'I met with those persons with disabilities who committed suicide just because they don't want to ask their parents to take them to the washroom. So they stop drinking water or having food because they thought if they had water or food, then they have to ask one of their family members to take them to the washroom. It will be a very unrespectable thing and they don't want to burden their parents. [...] So they committed suicide.'⁴⁸

While all disabled people face negative attitudes, participants in the research noted that people with intellectual, psychosocial and multiple disabilities are more susceptible to stigma. There are, of course, country specifics. For example, in some countries in Africa, it is believed that certain types of disability, such as cerebral palsy, are contagious, and people with this condition are avoided.

A key factor for negative public attitudes and the withdrawal of community support is the medical (individual) understanding of disability, which views disabled people through their impairment. As highlighted by a disability activist from Europe:



'In every culture, I think, the medical model of disability means limiting and restricting disabled people to their impairment and nothing else. And that is the problem with the medical model. And then it might take different cultural shapes. It might be a medical diagnosis. It might be combined with superstition. It might be the incapacity approach - you can't do anything because you are impaired. And all different shapes we can think of.'⁴⁹

45 See for example <http://paper.standartnews.com/en/article.php?d=2012-03-07&article=16971>.

46 National Disability Authority (2011) A national survey of public attitudes to disability in Ireland, available at: https://www.ucd.ie/t4cms/Public_Attitudes_to_Disability_in_Irelandfinal%20Report%202011.pdf, p.9, 35.

47 See, for example, Mansell, J. Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, p. 56; European Expert Group on the Transition from Institutional to Community-based Care (2012) *Common European guidelines on the transition from institutional to community-based care*, p. 122.

48 Consultation MENA.

49 Consultation Europe.

2.1 Influence of tradition and religion

Some traditional beliefs and religious interpretations associate disability with a punishment from God for wrongdoing, or with witchcraft.⁵⁰ This can lead to disabled people being avoided and excluded from the community or subjected to violence and abuse.⁵¹ Cases of disability hate crime – a type of crime resulting from negative attitudes against certain individuals or groups – are also reported in many high-income countries.⁵²

In some cultures, the social stigma attached to disability is transferred to the family and shapes its response to disability – ‘If you have a disability, that means that your family has a punishment from God’.⁵³ It can lead to unwillingness to seek any disability-related support, because this would question God’s authority, or it would expose the family’s behaviour.⁵⁴ Disabled people can also be kept locked, sometimes in inhumane conditions, and not allowed to go out, in order to protect the whole family from discrimination.⁵⁵ People who are unable to contribute to the economic or social activities of the family, usually people with high support needs, face greater discrimination.⁵⁶



‘They [disabled people] might not be allowed even to get out of that particular room [...]. So the person is not even allowed to go to the washroom or outside. They are fundamentally locked out in very inhumane conditions. [...] there is limited state support and high levels of poverty, so when a person requires a lot of care, and the family has other family members and other needs to be taken care of, then naturally, what the family will do, they will lock up that particular person. Sometimes women are locked up to prevent sexual abuse from the community.’⁵⁷

Culture and attitudes also affect the support provided by families and their contribution to independent living and inclusion. Negative attitudes can mean that family or community members are only willing to tend to the basic needs of the disabled person – ‘people may not speak with a person with psychosocial disabilities, but will not throw them out’.⁵⁸ Attitudes and culture can also lead to overprotection of disabled people by their families, to stifling their self-expression and denying them decisions about their lives.



‘Families are afraid to leave their child or to let people with disabilities make their own decisions... We have this kind of idea that if you let people with disability make their own decision, they will make a bad decision and will end up in the street. That is why we build institutions to protect them, in order not to end up in the street. We try to say aloud we have the right to make mistakes, we have the right to take risks, also we have the right to make bad choices as all of us. When they hear this, they say ‘no, no, no, risks are more important for you’. We have the same risks as others, we want to live in the community and make the same mistakes as others.’⁵⁹

50 Consultations Africa, Asia and the Pacific, North America, Europe, Middle East and North Africa (MENA).

51 Consultation Africa. See also Cimpric, A. (2010) *Children Accused of Witchcraft: An anthropological study of contemporary practices in Africa*, Dakar: UNICEF WCARO. Available at: https://www.unicef.org/wcaro/wcaro_children-accused-of-witchcraft-in-Africa.pdf

52 See, for example, ENIL (2014) *Disability hate crime: A guide for disabled people’s organisations, law enforcement agencies, national human rights institutions, media and other stakeholders*, available at: http://enil.eu/wp-content/uploads/2014/11/Disability_Hate_Crime_Guide-FINAL-ENG-1.pdf and Novis, A. (2010) *The bigger picture report*, available at: <http://dpac.uk.net/disability-hate-crime/>; Roulstone, A. and Mason-Bish, H. (2013) *Disability hate crime and violence*, London: Routledge.

53 Consultation MENA.

54 Klein, D. and Chen, D. (2001) *Working with children from culturally diverse backgrounds*. Canada: Delmar, p. 66.

55 Consultation Africa.

56 <http://www.rds.hawaii.edu/ojs/index.php/journal/article/viewFile/110/367>

57 Consultation Africa.

58 Consultations MENA.

59 Consultation MENA.

2.2 Medicalisation of disability

The understanding of disability is often medicalised. Disabled people, especially those with high support needs and people with intellectual and psychosocial disabilities, are still perceived as ‘abnormal’ and ‘ill’ and as unable to contribute to society.⁶⁰ This can lead to policies and practices that isolate and segregate disabled people in special residential facilities, special schools or special workplaces. Here again, this view is reinforced by the lack of community support and accessible services, which hinder disabled people’s participation in the community. For example, the lack of accessible teaching and learning methods, physical infrastructure, support with communication, personal assistance or mobility aids can reinforce the medical professionals’ and societal view that some children are ‘uneducable’. Disabled people can also be subjected to bullying, harassment and abuse (verbal and physical) by other members of the community.⁶¹

2.3 Individualism

In some cultures, where achievements are seen as an exclusively individual contribution, the dependence on other people for support leads to a diminished view of disabled people.⁶² According to Morris in the UK, ‘[N]egative values ascribed to any experience of depending on others and the associated meaning of ‘care’ have the result that the lives of people who need assistance are devalued.’⁶³

Disabled people may also be seen as unable to make decisions for themselves, which may result in paternalistic attitudes and practices, restricting their choice and control. People think ‘we have to make decisions for the [disabled] people as if we were parents [...] protecting them to make the right choice’.⁶⁴ Thus, certain groups of disabled people are perceived as unable to live independently and they are not allowed to do so.

Recommendations

- ▶ Awareness-raising campaigns should be organised as part of the measures to support disabled people’s independent living and inclusion in community.
 - In line with Article 8 of the CRPD, the campaigns should aim to ‘combat stereotypes, prejudices and harmful practices relating to persons with disabilities’, ‘foster respect for the rights and dignity of persons with disabilities’, and ‘promote awareness of the capabilities and contributions of persons with disabilities’.
 - Article 8 stresses the importance of implementing measures at different levels. This includes, for example, measures aimed at the media, such as guidance on how to portray disabled people in a manner consistent with the CRPD. Education system should also be included in awareness raising campaigns, as it has a key role in shaping people’s attitudes. Positive perceptions and understanding of the rights of disabled people should also be promoted at the family and community level, and society in general.
 - Awareness raising campaigns should take into account the local specifics. For example, in some countries, where traditional leaders in the community are important authority figures, they should be addressed as a priority, as they can influence family and community perceptions about disabled people.

60 See, for example, Report of the Special Rapporteur on the Rights of Persons with Disabilities on her visit to Moldova, 2 February 2016, available at: http://ap.ohchr.org/Documents/dpage_e.aspx?m=211.

61 European Union Agency for Fundamental Rights (2012) *Choice and control: the right to independent living*. Luxembourg: Publications Office of the European Union. Vienna: EU FRA, p.39-40.

62 Consultations, North America.

63 Morris, J. (2003) *Barriers to Independent Living: A Scoping Paper Prepared for the Human Rights Commission*, p. 58.

64 Consultation North America.

Chapter 3: Lack of support to the family

3.1 The importance of family support

The family has an important role in the lives of all people. Growing up in a family environment is essential for the 'full and harmonious development of the child'.⁶⁵ Equally, family support is important for disabled children and adults; it can prevent institutionalisation and can be essential for disabled people's participation in the community. With the 'necessary protection and assistance', families can 'contribute towards the full and equal enjoyment of the rights of persons with disabilities'.⁶⁶

Families, friends and the broader community are the main source of support for disabled people across the world. Informal support has an important place in countries with collectivistic and communal cultures, in which connections between people within a community are cherished and valued. Family ties and responsibilities in such cultures remain strong and the parents or the extended family usually take on the responsibility for looking after their disabled member.⁶⁷

Religion and culture are other important factors encouraging familial and community support, although usually from a charity perspective. For example, in Islam, it is the society's duty to care for those that are 'less fortunate', including disabled people, and Muslims are required to give a small percent of their income (Zakah) to support such people.⁶⁸ It is sometimes believed that families will get a reward from God for supporting their disabled member.⁶⁹ Some Christian traditions also promote compassion and encourage communities to provide support for disabled people, who are seen as victims of misfortune.⁷⁰

In individualistic, 'western' countries, community ties are generally looser and individual self-reliance is encouraged.⁷¹ However, even in countries with a relatively well developed system of formal support, most of the assistance comes from family and friends.⁷² For example, a study of disabled adults in the USA found that 70% of them relied on family and friends for assistance.⁷³

3.2 Problems caused by the lack of support to the family

Informal support is very important and needs to be encouraged. However, the lack of other support options and the exclusive reliance on family can have an adverse effect on disabled people's independence and inclusion. It can restrict their autonomy, as it does not allow for choice and control over assistance – 'If you are going to need help, you are going to have to let people help you the way that they want'.⁷⁴ In addition, without the 'necessary support from the state', families can find themselves unable to provide adequate assistance. They can also be forced to place their disabled member in an institution, when institutions are the

65 United Nations Convention on the Rights of the Child, Preamble.

66 CRPD, Preamble (x)

67 Consultations Africa, MENA, Latin America.

68 See Hagrass, H. (2005) 'Definitions of disability and disability policy in Egypt', in Barnes, C. and Mercer, G., eds., 'The social model of disability: Europe and the Majority World'. Leeds: The Disability Press, pp. 148 – 162.

69 Consultation MENA.

70 See Covey, H. (2004) 'Western's Christianity's two historical treatment of people with disabilities or mental illness', in *The Social Science Journal*, 42(1): 107-114.

71 Hofstede, G. (2001) *Culture's Consequences: Comparing Values, Behaviours, Institutions, and Organizations Across Nations*. Second Edition. Thousand Oaks, CA: Sage Publications, p. 225.

72 World Health Organisation and the World Bank (2011) *World report on disability*, Malta: WHO, p.139. Available at: http://www.who.int/disabilities/world_report/2011/report.pdf.

73 Hanson, K., Neuman, T. and Voris, M. (2001) *Understanding the health-care needs and experiences of people with disabilities*. Menlo Park: The Henry K. Kaiser Family Foundation.

74 Consultation North America.

only available ‘support’. Sometimes, families can be ‘pressed to place their children in such facilities or the children are even taken away from their homes in order to get a „better“ treatment’⁷⁵. Furthermore, there are people who do not have a family to support them, which means that when there are no other options, they may end up on the street and be subjected to violence. For example, the urban-rural migration in some countries has led to disappearance of ‘the natural supports that people enjoy in rural communities’, leaving disabled people ‘vulnerable to being homeless in urban settings’.⁷⁶

Finally, the lack of support has a negative impact on families as well. The additional disability-related costs and the loss of income of one of its members, who becomes a full or a part-time carer, can push the whole family deeper into poverty. Family members can also suffer from high levels of stress and fatigue. For example, a 2011 survey among people with intellectual disabilities and their families in the USA, found that the additional responsibilities of family members, related to the provision of support, interfered with their work (71%) and were a reason for them to leave work (20%). They also caused physical strain and fatigue (88%) and financial problems (81%).⁷⁷ Especially affected were women and girls who are traditionally the providers of care within the family.

Recommendations

- ▶ Measures should be taken to ensure the availability of a range of community support services and accessible mainstream services, that provide families with relief from their caregiving responsibilities and will allow them to remain included in the community.
- ▶ Awareness-raising campaigns should be organised to raise the awareness of families, as well as society as a whole, about the rights of disabled people.
- ▶ Information and personalised support should be provided to families to enable them ‘to contribute towards the full and equal enjoyment of the rights of persons with disabilities’.⁷⁸

⁷⁵ BRK – Allianz (n. 37)

⁷⁶ USP-K (2016) USP-K submission on the rights of persons with disabilities to live independently and be included in the community. Day of General Discussion on Article 19 of the UN CRPD, para. 12.

⁷⁷ Anderson, L.L., Larson, S.A., & Wuorio, A. (2011). 2010 FINDS National Survey Technical Report Part 1: Family Caregiver Survey. Minneapolis: University of Minnesota, Research and Training Center on Community Living. Available at: <http://www.thearc.org/document.doc?id=3673> ;

⁷⁸ CRPD, Preamble (x).

Chapter 4: Prevalence of institutional services

4.1 Traditional institutional care

In many countries around the world, disabled people continue to be placed in long-stay residential institutions, often housing hundreds of disabled people and located in remote places. Institutionalisation is a fundamental barrier to the realisation of disabled people's right to independent living, as envisaged by Article 19, because it deprives disabled people of the opportunity to make even basic decisions about their daily lives and condemns them to isolation. 'Institutions are therefore not an option where "choices equal to others" can be practiced'⁷⁹. There are numerous reports about the inhumane and degrading conditions which disabled people in institutions are subjected to, about the coercion, violence and abuse in institutional care settings in both high and low income countries.⁸⁰ Disabled people are often placed in institutions against their will⁸¹ or are forced to 'choose' this option due to the lack of quality, accessible and affordable community services, the various restrictions related to the access to services, and the attitudes of professionals.

For centuries, state-supported institutionalisation has been the main housing and/or care option for disabled people in the countries of Europe and North America, former USSR, Australia, and New Zealand. In the second half of the 20th century, a move towards deinstitutionalisation began, influenced by disabled people's movement, and more recently, by the CRPD. However, despite the continuous work towards deinstitutionalisation and the closure of many residential facilities, institutions remain far too common. There are still countries without comprehensive plans for deinstitutionalisation.⁸² In some countries, long-stay residential institutions continue to be the only option for people with high and complex support needs, including people with intellectual and psychosocial disabilities.⁸³ There is also a worrying tendency towards increase in the number of disabled people in institutions.⁸⁴

In many low-income countries of Latin America, Africa and partly Asia and the Pacific, traditional residential institutions are not that widespread⁸⁵. Still, as was revealed by our research, the practice of institutionalisation does exist and is common in some of the countries where 'the state has created large institutional infrastructure to place poppers, people with leprosy, disabled people...'.⁸⁶ It is a major concern that institutions are being seen as 'the best option for care for disabled people' in places where they had

79 Council of Europe Commissioner for Human Rights (2012) *The right of people with disabilities to live independently and be included in the community*. Issue paper. Available at: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>, p. 29.

80 See, for example: <http://enil.eu/news/death-by-malpractice-in-an-institution-in-the-netherlands/> (on the Netherlands); <http://archive.enil.eu/news/disability-watchdog/un-special-rapporteur-on-torture-calls-for-an-investigation-by-the-us-department-of-justice-into-the-use-of-shock-on-children-with-disabilities-in-the-united-states/> (on the USA), <https://www.hrw.org/news/2015/10/25/somaliland-people-disabilities-abused-neglected> (on Somalia), http://www.driadvocacy.org/wp-content/uploads/Sin-Justicia-MexRep_21_Abr_english-1.pdf (on Mexico), <http://www.driadvocacy.org/wp-content/uploads/Serbia-rep-english.pdf> (on Serbia); <https://www.hrw.org/report/2014/09/15/abandoned-state/violence-neglect-and-isolation-children-disabilities-russian> (on Russia); <https://www.theguardian.com/commentisfree/2010/oct/07/mental-health-provision-nepal> (on Nepal), <http://www.sciencedirect.com/science/article/pii/S0140673605755343> (on India).

81 See section Substitute decision-making.

82 See for example, Austrian Civil Society Representatives (2013) Responses of Austrian civil society representatives with regard to the List of Issues of the UN-Committee on the Rights of Persons with Disabilities, p. 9; Korean Disability Forum (2014) *Parallel report under the CRPD for Republic of Korea*, para. 37.

83 (2016) Belarus Zero Report on the CRPD, para. 101. Available at http://www.enil.eu/wp-content/uploads/2016/07/Zero_report_english.pdf.

84 Directorate General for Internal Policies, Policy Department C: Citizens' Rights and Constitutional Affairs. (2016) *European Structural and Investment Funds and people with disabilities in the European Union*, p. 19, available at: [http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL_STU\(2016\)571386_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL_STU(2016)571386_EN.pdf).

85 See WHO and the World Bank (n. 58), p. 145.

86 Consultation Asia and Pacific. 'Poppers', in this context, refers to drug users.

previously not existed.⁸⁷ Plans to expand or to build new institutions are included in policy documents in a number of countries.⁸⁸

Investments in the building of institutions, or renovation of existing institutions, continue even in countries, which have ratified the CRPD.⁸⁹ This is a serious hindrance to the development of community-based services, as it takes away resources that otherwise could be invested into support in the community.

Frequently asked questions:

Question 1 – Can disabled people choose to live in an institution?

Often the decision to live in an institution is not a matter of individual preferences, but a consequence of the lack of options to choose from. When people do not have a place to live, or the institution is the only place they can get support from, they are forced to ‘choose’ to live in an institution.



In my country, we asked persons with disabilities living in institutions if they would want to return to their homes in their communities. Many of them said no. I said why? They said because the support services are within the institutions [...]⁹⁰

People may also ‘choose’ institutional settings because they are used to them – they have spent a significant part of their life in an institution and may find it difficult to imagine a different life. Sometimes, they may not have the confidence and the skills to make decisions for themselves, as they have never been allowed to do so. People’s vision and choices can also be limited by negative community attitudes and beliefs⁹¹ or by the lack of information about other options.

It is impossible to claim that some disabled people choose to live in an institution, as if they were on a level playing field with others. Disabled people can have a genuine choice only in a truly inclusive and accessible community, with a range of adequate and quality support options, including from peers.

⁸⁷ Consultation Africa.

⁸⁸ See, for example, Report of the Special Rapporteur on the Rights of Persons with Disabilities Paraguay on her visit to Paraguay, 21 December, 2016, para. 59, available at: http://ap.ohchr.org/Documents/dpage_e.aspx?m=211. Disability Rights International and the Comisión Mexicana de Defensa y Promoción de los Derechos Humanos (2010) *Abandoned and disappeared - Mexico's segregation and abuse of children and adults with disabilities*, p. xiv, available at: <https://www.driadvocacy.org/media-gallery/our-reports-publications/>

⁸⁹ ECCL (2010) *Wasted Time, Wasted Money, Wasted Lives ... A Wasted Opportunity? – A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services*, available at: <http://community-living.info/wp-content/uploads/2014/02/ECCL-StructuralFundsReport-final-WEB.pdf>; ENIL-ECCL (2013) *Briefing on Structural Funds investments for people with disabilities: achieving the transition from institutional care to community living*, available at: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf>

⁹⁰ Consultation Africa.

⁹¹ Inclusion international (2012) *Inclusive communities = stronger communities. Global report on Article 19: The right to live independently and be included in the community*, p. 66, available at: <http://inclusion-international.org/wp-content/uploads/2013/07/Global-Report-Living-Colour-dr2-2.pdf>

4.2 Contemporary institutions

Institutions are more than bricks and mortar; there are other important characteristics that make a particular setting ‘an institution’:

“ ‘An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.’⁹²

“ ‘Institutional care [can be defined] as any residential care where: users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; the requirements of the organisation itself tend to take precedence over the users’ individualised needs.’⁹³

The institutionalisation of disabled people does not always occur in traditional, large-scale residential settings, housing hundreds of disabled people, and located in remote places. Contemporary institutions are often located in cities or towns and can accommodate a smaller number of people (although there are examples of contemporary institutions for tens and for hundreds of people). They are referred to as ‘group homes’, ‘family-type centres’, ‘protected houses’, ‘living centres’ or, quite misleadingly, ‘community living centres’ or ‘centres for excellence’.⁹⁴ Such facilities exist in many countries in Europe and North America and in other countries with a history of institutionalisation of disabled people. Often, they are presented as innovative solutions to the problems of exclusion disabled people face.⁹⁵

The problem with such contemporary institutions is that they group people, based on a single characteristic – the presence of an impairment – and set them apart from the rest of the community, thus perpetuating their isolation and segregation. Thus, even when physically located in the community, they make genuine engagement with the community impossible. In addition, while significantly downsized (accommodating, for example, 10-12 people), such settings remain institutional in character as they restrict people’s every-day choice. Often, residents are not allowed to make even simple decisions, for example, about when to go to bed or get up, and are required to follow the rules, developed by the organisation. Residents may lack privacy and be subjected to constant surveillance⁹⁶. Many do not have access to their own mail or bank accounts and are not allowed to live with their family or friends.⁹⁷ The service is provided in a paternalistic way and personal views and opinions are often dismissed; for example, by labelling people ‘conflicting’ or ‘uncooperative’.

92 European Coalition for Community Living (2009) *Focus on article 19 of the UN Convention on the Rights of Persons with Disabilities*, p. 10, available at: <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf>

93 European Commission (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, p. 9, available at: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes>

94 Inclusion international (n. 90), p. 84.

95 Disability representative, advocacy and human rights organisations (2012) *Disability rights now: civil society report to the United Nations Committee on the Rights of Persons with Disabilities*, para. 337, available at: <http://www.afdo.org.au/media/1210/crpd-civilsocietyreport2012-1.pdf>

96 European Union Agency for Fundamental Rights (n. 60), p. 40.

97 Convention Coalition Monitoring Group (2012) *Disability rights in Aotearoa New Zealand 2012: a report on the human rights of disabled people in Aotearoa New Zealand*, p. 30, available at: <http://www.dpa.org.nz/resources/sector-resources/the-convention-disability-rights-in-aotearoa-new-zealand/2012-monitoring-reports>.

4.2.1 Experiences of people living in contemporary institutions

Often the decision to live in an institution is not a matter of individual preferences, but a consequence of the lack of options to choose from. When people do not have a place to live, or the institution is the only place they can get support from, they are forced to ‘choose’ to live in an institution.

“ ‘They [the staff] write some plans – something about my daily live – they say I am a conflict person, I don’t want to wear shoes, I impose my opinion on the staff’.

“ ‘When you are placed [in a small group setting], you can’t think independently, you can’t make independent decision, you don’t have control over your life, nothing depends on you.’

“ ‘You constantly feel humiliated.’ ⁹⁸

“ ‘...the users of the Hope House [a type of group home] are not involved in any simple decision concerning the administration of the House such as shopping, cooking, etc. The daily routine consists of medication and social activities and courses in the house. Participation in and cohesion with the social life do not exist at all, we are all under custody.’⁹⁹

“ ‘Now the staff have decided that the residents must “have a break” in their own flats, so that the pedagogues can eat in the common room in peace. They (the residents) are given a kind of watch, so that they can see when they are allowed to use their own common room again and when the staff can be disturbed once more’.¹⁰⁰

A key problem with many contemporary institutions is that they tie the provision of support to housing. Thus, people who need support are forced to accept a ‘group home’ type living arrangement, and vice versa – people who need a place to live are forced to accept the support provided there. This is in violation of Article 19 of the CRPD, which explicitly states that disabled people should not be ‘obliged to live in a particular living arrangement’.

The problem with institutionalisation is not limited to state-funded facilities. There are numerous institutions, established by religious groups, charities or privately run, violating the rights of disabled people. In low-income countries, privately run centres for disabled people are often ‘places of detention and solitude, where people are chained and beaten’¹⁰¹ and which they cannot leave. The lack of other support in the community leads to high demand for residential placements and to proliferation of such places.¹⁰² It has been suggested that as part of the process of de-institutionalisation in high-income countries, ‘we also left a back door open for the private sector to create new institutions, typically claiming to offer some specialised services (‘assessment and treatment’), while actually warehousing people for profit’.¹⁰³

98 Centre for Independent Living (2016) *Deinstitutionalizatsiata e skupa, no nishto ne struva!* [De-institutionalisation is expensive but it does not do the job!], p. 19, available at: <http://cil.bg/userfiles/nabliudatelnitsa/Report-DI-Final.pdf> [in Bulgarian].

99 RUSIHAK (2014) Tuzla Hope House Visit, quoted in Roadmap for the implementation of Article 19 of the Convention on the Rights of Persons with Disabilities in Turkey (2015), p. 11, available at: <http://ilnet.enil.eu/wp-content/uploads/2016/02/Roadmap-draft-23Dec2015.pdf>.

100 Gruber, T. and Andersen, H. (2013) ‘It looks just like a nursing home’, *LEV-Magazine*, no 4, 2013, available in English at: http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DNK/INT_CRPD_CSS_DNK_18209_E.doc

101 Human Rights Watch (2015, October 25) *Somaliland: people with disabilities abused, neglected*, available at: <https://www.hrw.org/news/2015/10/25/somaliland-people-disabilities-abused-neglected>.

102 Ibid.

103 Towell, D. (2013) ‘The 21st century challenge: building sustainable and inclusive communities’, in *Institution Watch* 7(2), p. 2, available at: <http://www.cacl.ca/sites/default/files/institutionwatchfall2013.pdf>.

Frequently asked questions: Question 2 – Are group homes in line with Article 19?

There are numerous problems with relying on group homes as the preferred form of living arrangement for disabled people. Apart from the institutional character of many such settings¹⁰⁴, a key problem with group homes is that they require disabled people to leave their families and communities and to live with people they often do not know, depriving them of a genuine choice where and with whom to live. For those moving from large institutional facilities, group homes may represent a step towards living in the community, but one where their choices and freedoms continue to be restricted.

Disabled people may choose to live together with other disabled people, and if that is the case, they should be supported to do so. However:

- 1) this should be their choice. This means that there should be a range of genuine independent living options in the community, to allow for real choice. Adequate information and support, including from peers, should also be provided to assist with decision-making.
- 2) the place they live should resemble a home. This requires that:
 - the number of people living together is not higher than usual. For example, if most apartments or houses accommodate 4 – 6 people, the same should apply when it comes to disabled people wishing to live together.
 - the provision of support and housing is separated, to allow for greater flexibility. Thus, if someone is unhappy about the services they receive, they might decide to change the service provider and continue to live in the same place with the same people.
 - there is no block treatment – provision of services is personalised and depends on individual needs and preferences. Block treatment, where all people living in a certain place receive the same services, is one of the key characteristics of institutional culture.
 - people can make choices about their daily lives – for example, when to get up and go to bed, what to eat, whether to go out and when, whether to have friends over etc.
 - individual privacy is respected and people have personal space and belongings.
 - mainstream services and facilities in the area are accessible, so that disabled people are able to use the local transport options, go to work, see the local doctor, use the local hairdresser, access cultural and sports facilities etc.

104 See section 'Prevalence of segregating services', sections 'Contemporary institutions' and 'Re-institutionalisation – when de-institutionalisation goes wrong'.

4.3 Non-residential institutions

There are non-residential services that are physically located within the community, but that do not facilitate social inclusion. Examples of such services, widely available in high- and some middle-income countries, are day-care centres and sheltered workshops. These services do not support participation in society, but create a parallel system for disabled people, which perpetuates their isolation and segregation. Instead of supporting disabled people's autonomy, they can make them dependent. Investments in such services take away resources from other, genuine community-based services that support full inclusion and participation in society.

4.4 Institutionalisation in the community and at home

Many disabled people who live in the community – with their families or alone – remain isolated and excluded from the community. They cannot leave their homes, do not have access to basic services, such as education and health, they are not able to interact with other members of the community, to marry or have children.¹⁰⁵ They can be subjected to violence or can live in inhumane and degrading conditions.¹⁰⁶ Their confinement is a result of a number of factors, including inaccessible physical environment, inaccessible and unaffordable mainstream services, inadequate support services, poverty, stigma and negative attitudes.

Institutionalisation can also happen in the community when relationships with professionals remain unequal and people are forced to accept certain treatment. Such coercive care in the community, sometimes referred to as 'institutionalisation without walls'¹⁰⁷, has been introduced in many high-income countries as part of efforts to close residential institutions. An example of this approach is the use of powers (sometimes referred to as 'Community Treatment Orders'), which suspend forced institutionalisation on the condition that the person accepts forced psychiatric treatment in the community.¹⁰⁸ Forced psychiatric treatment in the community is also a practice in some low-income countries.



'People refuse to go to hospitals, so the doctors come and provide forced treatment in your home. So, they will not take you to an institution, but they will come and inject you by force, inside your house... Forced treatment is not only in institutions, it is also within the community where the medical practitioners in collaboration with the family and maybe the area chief or the local administration police will do it within the community.'¹⁰⁹

4.5 Re-institutionalisation – when deinstitutionalisation goes wrong

Many countries with systems of traditional residential institutions have recognised the need for deinstitutionalisation and have taken steps towards transition from institutional to community-based services. There are, however, numerous problems in the way deinstitutionalisation is planned and implemented in many countries that compromise its potential to foster disabled people's independent living and partici-

105 Consultations Africa, Asia and the Pacific, Europe, Latin America, MENA, North America.

106 See section Attitudes and culture.

107 Priebe, S. (2004) 'Institutionalization revisited – with and without walls', in *Acta Psychiatrica Scandinavica* 110, pp. 81-82.

108 ENUSP (2016) *Submission of the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) for the Day of General Discussion (DGD) on the right of persons with disabilities to live independently and be included in the community*, p. 20, available at: http://www.ohchr.org/Documents/HRBodies/CRPD/DGD/2016/EuropeanNetworkof_Ex_Users_and_Survivors_Psychiatry-ENUSP.doc

109 Consultation Africa.

pation in community. According to one commentator, ‘many of the support and services created ... to facilitate deinstitutionalisation, are now the very structures that stand in the way of their [disabled people’s] full inclusion’.¹¹⁰

Often, deinstitutionalisation is understood to mean simply closing down large-scale residential institutions. In other words, the closure of residential institutions is seen as an end, rather than a means to an end, facilitating disabled people’s independent living and participation in the community. As a result, people are moved from traditional to contemporary institutions and little attention is paid to the development of a range of support services and to making community services accessible. ‘Group-home’ types of settings are commonly presented as a ‘stepping stone’ to real life in the community, but remain a permanent ‘home’ for people leaving institutions. In the context of poorly developed support options, their existence encourages the ‘placement’ of disabled people and prevents real inclusion. A recent experience with deinstitutionalisation of care for children shows that the number of children in group homes and foster care increases when fewer investments are made in the development of support services in community that enable children to stay with their families.¹¹¹

Many countries ‘are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively at people with disabilities’.¹¹² Some of the newly built complexes or redeveloped institutions house up to 100 people under the same roof.¹¹³

The desire to close institutions quickly can mean that people affected are not consulted and their desires are not taken into account. The decisions about where and with whom to live are made for them by service providers and/or professionals.



‘In a dehumanising transition process, an auction was organised with representatives of group home businesses where a ‘state official read aloud medical histories of residents with intellectual and developmental disabilities prompting group home officials to raise their hands for desired picks’. Following complaints, the only change introduced was that the auction process became ‘silent’, meaning that ‘group home officials marked preferred resident selections on paper’.¹¹⁴

Poorly prepared and implemented transition process can also be damaging for disabled people. Recently, a flawed relocation process has led to the death of tens of disabled people.¹¹⁵

While deinstitutionalisation is the right approach, in line with Article 19¹¹⁶, special efforts should be made to ensure that it does not create more problems than it solves. The recommendations below seek to address some of the common challenges related to deinstitutionalisation.

110 Larson, L. and Haddad, S. (2013) Message from the Task Force, *Institution Watch*, Fall 2013. Available at: <http://www.cacl.ca/sites/default/files/institutionwatchfall2013.pdf>

111 Lumos (2015) *Ending institutionalisation*, p. 5 – 6, available at: https://wearelumos.org/sites/default/files/Finance_BG_online_final_2.pdf

112 Council of Europe Commissioner for Human Rights (n. 78), p. 113.

113 Disability representative, advocacy and human rights organisations (n. 93), p. 129; Collaborating group (2014) *Responses from the Danish Disability movement to List of Issues from the CRPD-Committee, RPD/C/DK/Q/1, April 17th 2014*, available at: http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DNK/INT_CRPD_CSS_DNK_18208_E.doc

114 Berens, M. and Callahan, P. (2017) ‘A troubled transition. In the rush to close institutions, Illinois Ignored Serious Problems in Group Homes. *Chicago Tribune*, 10 January 2017. Available at: <http://www.chicagotribune.com/news/watchdog/grouphomes/ct-group-home-investigations-cila-met-20161229-htmlstory.html>.

115 ‘South Africa: UN experts shocked by death of at least 37 people in flawed relocation process from psychiatric hospitals’, *UN OHCHR*, Geneva, 2 December 2016 <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20981&LangID=E>.

116 As mentioned earlier, the CRPD Committee, in its Concluding Observations, has made numerous recommendations to states to take actions towards de-institutionalisation.

Recommendations

► Deinstitutionalisation and de-segregation of service provision

- A comprehensive deinstitutionalisation strategy should be adopted with a reasonable timeframe¹¹⁷, benchmarks and a sufficient budget. It is important to ensure that:
 - the strategy is based on human rights principles, that is, it promotes independent living and the full inclusion and participation in society of disabled people as a right.
 - the measures included in the strategy cover all disabled people, regardless of the type and degree of their impairment, or age.
 - the measures aimed at closing residential institutions are accompanied by measures aimed at developing community-based services and making mainstream services accessible. This will ensure that the deinstitutionalisation process goes beyond the closure of institutions and contributes to disabled people's participation in the community, without replacing one type of institutionalisation with another.
 - all key aspects, needed to ensure a smooth and sustainable transition to quality community-based support, are covered. For example, legal framework, funding, workforce development, quality standards, and awareness raising.¹¹⁸
- Investments in the building of new institutions or expansion and renovation of residential institutions should be prohibited or limited to actions necessary to address risk to residents' health and safety.¹¹⁹ Together with this, spending on institutional care should be gradually reduced and funds should be transferred to services in the community. Investments into group homes, and similar services, should not be prioritised in the deinstitutionalisation process. Where residential services, such as group homes are developed, they should be one of the options, alongside other genuine independent living options.¹²⁰
- Disabled people and their organisations should be consulted and involved in the planning and implementation of deinstitutionalisation measures.

117 Critiques have been raised towards deinstitutionalisation strategies for setting long time frames. See, for example, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (1728 September 2012), para. 33, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f-C%2fHUN%2fCO%2f1&Lang=en.

118 For more details, see European Expert Group (n. 46), Chapter 3.

119 European Coalition for Community Living (n. 10), p. 12.

120 See ENIL definition of community-based services, Annex 1.

Chapter 5: Barriers related to community support services

Access to quality, affordable and accessible support services in the community is an essential precondition for ensuring that disabled people can live and participate in the community as equal citizens – the vision of Article 19. Support services can also help overcome environmental barriers, many of which stem from inaccessible mainstream services.

At the same time, the lack or the inadequate provision of such services can reduce disabled people's ability to make choices about their lives and can condemn them to isolation – at home or in a residential institution. Some of the key concerns, related to the provision of community support include a) poor availability, accessibility and affordability of support, b) restrictions placed on disabled people's access to services, c) poor quality of services, and d) inadequate funding.

5.1 Availability, accessibility and affordability of support

5.1.1 Poor availability of support in the community

Community support for disabled people comprises a wide range of measures and interventions, such as personal assistance, communication assistance (for example, sign language interpreters, alternative and augmentative communication), technical aids and assistive technologies, support persons, peer support, housing and other. For many disabled people, support is an essential precondition for overcoming environmental and attitudinal barriers and realising their right to live independently and be included in the community.

Despite their huge importance, support services remain underdeveloped in all regions of the world¹²¹. In many low- and middle-income countries, formal services and programmes for disabled people are still 'a fairly new concept'.¹²² Consultations with people from Asia, Africa and Latin America confirmed that in many countries in these regions, formal services are totally absent or merely symbolic. Support services that are key to disabled people's participation in the community, such as personal assistance and support with decision making, are not developed, and, there is a limited availability of sign language interpreters and mobility aids.

In most high-income countries, there is a wider range of support services. Despite that, funding and development of community-based services in many countries remains inadequate.¹²³ For example, deaf people can find it impossible to access sign language interpretation, with the ratio of sign language users to sign language interpreters in some countries being 2500:1.¹²⁴ Where available, personal assistance hours can be insufficient or even symbolic; for example, limited to 3 hours per day or 10 hours per year.¹²⁵ Often, available services are not sufficient to meet the full range of support needs and disabled people are put on waiting lists. These lists can include tens of hundreds of people, some of whom are waiting for several years to access crucial services related to housing, personal assistance and employment.¹²⁶ States' failure

121 WHO and the World Bank (n. 71), p. 137.

122 Ibid., p. 143.

123 Directorate General for Internal Policies (n. 83), p. 24; Consultations North America.

124 European Parliament Resolution of 23 November 2016 on sign languages and professional sign language interpreters (2016/2952(RSP)), J, available at: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2016-0442+0+DOC+XML+V0//EN>

125 European Union Agency for Fundamental Rights (n. 60), p. 32.

126 For example, in 2010 in the Flemish Community in Belgium nearly 22 000 disabled people were on waiting lists, of whom 14 155 were related to an urgent situation (See European Committee for Social Rights (2013) Decision on the Merits, 18 March 2013. International Federation for Human Rights v Belgium, available at: <http://hudoc.esc.coe.int/eng#%7B%22ESCDc-Type%22:%5B%22DEC%22%5D,%22ESCStateParty%22:%5B%22BEL%22%5D%7D>). In 2011 in the USA people with intellectual disabilities were

to provide a sufficient number and variety of support solutions forces people to go into residential care or increases their reliance on informal support from family and friends.



‘...there is a limited number of places and long waiting lists [for home and community-based services]. There will be a waiting list of many years to get these. You have to wait for someone else to die before starting to receive support. In the meantime, either you have to get by with family support...or people would have to go a nursing home, something like an institution, because they are not getting anything in the community and they can’t get anything in the community and they can’t live without this support. And they will be staying in these nursing homes while they are on the waiting lists.’¹²⁷

Frequently asked questions:

Question 3 – In the context of lacking support services and limited funding – where to start?

When planning the development of services in countries with limited or no community support, it is important to ensure that:

- There is a good understanding of the CRPD philosophy and the Article 3 principles, including respect for inherent dignity, the freedom to make one’s own choices, independence and full and effective participation and inclusion in society. It should also be understood that the CRPD covers all disabled people, which means that all disabled people can live independently and be included in the community. Such an understanding will help ensure that the planned measures are in line with the CRPD and do not reproduce segregation and exclusion.
- The local specificities are taken into account. Services that are being developed should respect the cultural norms, while at the same time providing disabled people with choice and control over their assistance, supporting their inclusion in the community.
- Other barriers hindering inclusion, such as attitudes, accessibility, discrimination are also considered.

The planned measures should:

- seek to provide access to individualised support for disabled people (e.g. personal assistance, supported decision-making, counselling, sign-language interpreters) and to technical aids and assistive devices. Together with this, support should be provided to families. It should be possible to combine informal and formal support.
- include awareness raising activities, aimed at building the capacity of key stakeholders (politicians, professionals, media, disabled people and their organisations, families and communities), as well as legal reforms.
- not be limited to supporting disabled people with their basic needs, but should seek to support their active participation in community.

waiting an average of 5.3 years for access to fundamental services, including housing, personal assistance, managing finances, and employment support (See The Arc (2011) *The Arc’s landmark report: still in the shadows with their future uncertain*, p. 2, available at: <http://www.arcwestcentral.org/FINDS%20Survey%20--%20Summary%20Key%20Findings.doc>.

¹²⁷ Consultation North America.

5.1.2 Availability of services depends on the place of residence

In most countries, low- and high-income, availability of services depends on where the person lives.¹²⁸ This is sometimes referred to as ‘postcode lottery’ in which a person’s address determines the support they receive and whether they will be able to participate in the community – to work, raise children, socialise – or they will have to live a restricted life. Disabled people’s rights to freedom of movement and choice of residence are also restricted, as they may not be able to keep the same type and level of support when moving to another neighbourhood or region. Disabled people living in the European Union (EU) face similar problems, as the lack of portability of support between the EU Member States does not allow them to move freely, unlike other EU citizens.¹²⁹

Often, there is an urban-rural divide – more diverse services are available in the cities, while people living in the rural areas may find it difficult to access even the basic services.¹³⁰ Even pilot projects and services provided by NGOs tend to be concentrated in the cities. This can disproportionately affect indigenous persons and certain minority groups who live predominantly in rural and more remote regions.¹³¹

Uneven distribution of services is directly related to decentralisation of service provision. With the devolution of powers and funds from the central to local government, the decision about how to spend the money is left to the local authorities. Although the purpose of the devolution is to make services more responsive to the needs of disabled people locally, the decisions on how the money is spent are influenced by a number of factors, including budget cuts, and are not necessarily led by the needs of disabled people locally, even when money is available.¹³²

5.1.3 Provision of services is unsustainable

Sustainable provision of services is essential for independent living and inclusion in the community of those disabled people who require long-term support. However, sustainability remains a key challenge in all parts of the world. In low-income countries, formal services, where available, are usually provided by charities and international non-governmental organisations¹³³, without a long-term policy and funding by the government. At the same time, in many high-income countries there is a tendency towards reducing state funding and transferring responsibility for the support to community organisations. Availability and sustainability of support is thus dependent on community and NGO resources and priorities. Informal support, widely used in all countries, may also be unsustainable, because family members may not be able to provide such support as they grow older or if they fall ill.¹³⁴

In the countries of Central and Eastern Europe (CEE), certain community services are financed on the basis of short-term, project-based initiatives, supported by the state and the EU funds. Such funding leads to constant uncertainty among disabled people in relation to their support and takes away their control over their assistance and lives. For example, projects for the provision of personal assistance services can be as short as one, or one and a half years. After this period, service providers can usually apply for a new project. However, if the provider does not apply or the project is not approved, the service is discontinued.

128 Consultations Asia and the Pacific, Africa and Europe.

129 Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM/2010/0636 final, p.5.

130 Consultations Africa, Asia and the Pacific, Latin America. See also the Report of the Special Rapporteur on the rights of persons with disabilities on her visit to Zambia, 19 December, 2016, available at: http://ap.ohchr.org/Documents/dpage_e.aspx?m=211, para. 31.

131 Disability representative, advocacy and human rights organisations (n. 93).

132 Inclusion London (n.d.) *One year on: evaluating the impact of the closure of the Independent Living Fund*, para. 8.2.2, available at: https://www.inclusionlondon.org.uk/wp-content/uploads/2016/09/ILF_Report.pdf.

133 Report of the Special Rapporteur on the rights of persons with disabilities, 20 December 2016, A/HRC/34/58, para. 60, available at: http://ap.ohchr.org/Documents/dpage_e.aspx?m=211.

134 WHO and The World Bank (n. 71), p. 142.

5.2 Restricted access to services

Even when there is a range of support services in the community, disabled people's access can be significantly restricted. States can introduce specific eligibility criteria and conditionalities, aimed to limit the number of people using services. Often, there are additional structural barriers in the application and assessment process, such as an overly complicated and long application process or the requirement for financial contribution.

5.2.1 Eligibility and conditionality

Eligibility criteria are used by the countries to determine who is entitled to use a particular service. These criteria are often discriminatory, as they exclude certain groups of disabled people, directly or indirectly, and fail to adequately take into account disabled people's support needs.

A common type of formal restriction in many countries is '*means testing*', which makes the use of services conditional on income. It means that people with income above a certain threshold, determined by the authorities, do not have free access to services, regardless of their needs. If they want to use a service, they are required to contribute financially to its cost, either partially or fully.¹³⁵ There are several problems with such arrangement. Firstly, it does not take into account the additional disability-related costs. Many people who have enough funds to support themselves, and are therefore above the threshold, do not have the resources to pay for additional disability-related support, which they need. People with higher support needs are especially strongly affected. Secondly, the threshold is often based on the household, rather than on the individual income. As a result, it can be difficult for a disabled person, whose partner has a full time job, to satisfy eligibility criteria¹³⁶ or the family can reject support as it increases the financial burden on the family as a whole.¹³⁷ Thirdly, if a person starts a job, their income can move them above the threshold. This can make it impossible for them to stay in employment, as they are not able to cover the additional disability-related costs.¹³⁸ Overall, linking eligibility for services to income leaves many disabled people without access to support and discourages them from seeking employment. As noted by Beresford:



'Means testing always hurts people who are neither rich or very poor. Because there's always a cut off point, some who are far from well off and who would "genuinely" benefit from them [services] are excluded.'¹³⁹

Other formal restrictions of access to services, applied in many countries, include the '*type*' and '*severity of impairment and age*'. For example, people with intellectual and psychosocial disabilities, children and older people are often excluded from support services, such as personal assistance.¹⁴⁰ Certain services can only be available to people with 'severe' impairments, or vice versa.¹⁴¹

135 Consultations Europe and Africa.

136 Consultation North America.

137 Korean DPO and NGO Coalition for UN CRPD Parallel Report (2014) *Parallel report for the UN Committee on the Rights of Persons with Disabilities*, para. 59.

138 Report of the Special Rapporteur on the rights of persons with disabilities, A/70/297, 7 August, 2015, available at: http://www.un.org/en/ga/search/view_doc.asp?symbol=A/70/297, para. 52.; Inclusion International (n. 90), p. 72.

139 Beresford, P. (2013, 14 January) 'Why means testing benefits is not efficient or fair', *The Guardian*, available at: <https://www.theguardian.com/social-care-network/2013/jan/14/means-testing-benefits-not-efficient-fair>.

140 See, for example, Korean DPO and NGO Coalition for UN CRPD Parallel Report (n. 116) and Austrian Civil Society Representatives (n. 81).

141 Concluding observations of the Committee on the Rights of Persons with Disabilities, Spain, CRPD/C/ESP/CO/1, para. 39, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fESP%2fCO%2f1&Lang=en.

Disabled people who *live with their spouse or other family members* can also have limited access to state-funded assistance. The responsibility for their support is transferred to their extended family, regardless of their preferences and the family's willingness and ability to provide adequate support.¹⁴²



'The criteria say, if you are living within the context of your family, that means you are not eligible for 'supported living'.¹⁴³



'[...] only single persons with disabilities with no parents and relatives to support them can be placed in care homes [the only formal option for support for people with high support needs]...¹⁴⁴

This is a serious barrier to independent living and self-determination of disabled people and their family members. It significantly limits disabled people's choice and control over their lives, including the choice of where and with whom to live. Following the financial crisis and the cuts in funding for services, further restrictions have been introduced in high-income countries, making it even harder for disabled people living with their families to receive support.¹⁴⁵

As highlighted by academics, the introduction of *workfare conditionality* is another barrier to access to services, especially for people who find it difficult to engage in paid employment, due to attitudinal and environmental barriers and the nature of their impairment. It makes access to benefits and services conditional on preparing for or engaging in paid employment. According to Mladenov, workfare conditionality can be explicitly stated or incorporated in the assessment process, or in the restrictions related to how the support can be used. For example, engagement in education and employment-related activity can be awarded disproportionately more points in the assessment process, making it the main criterion for granting access to assistance.¹⁴⁶ Bonfils and Askheim point out that such engagement may also be required to retain the support.¹⁴⁷

Legal provisions can also serve as a barrier, by *prioritising placement in segregating services* to support in community. For example, access to support at home or at school can be refused if a person is eligible for special provisions, such as special schools and residential settings.¹⁴⁸

5.2.2 Financial incentives for residential care provision

Some countries have introduced limits ('cost ceilings') on the support people can receive to live in their own homes, which effectively restricts access of people with higher support needs to services in the community. The limits are usually set in relation to the comparative costs of residential care. Expenses for community support services are covered 'if this service does not entail "disproportionate additional costs" when compared to a "reasonable" ... in-patient option (such as living in a care facility...)'¹⁴⁹. Since support in the community for people with very high support needs is likely to cost more, when compared to resi-

142 Consultations Europe, North America, Asia and the Pacific.

143 Consultation Asia and the Pacific.

144 Disabled People's Organisations of Mongolia (2015) *Submission to the CRPD Committee of the Response to the List of Issues on Mongolia*, p. 24.

145 See section Austerity measures. See also Brennan, C., Traustadóttir, R., Anderberg, P., and Rice, J. (2016) 'Are cutbacks to personal assistance violating Sweden's obligations under the UN Convention on the Rights of Persons with Disabilities?', *Laws* 5(23).

146 Mladenov, T. (2016) 'Governing through personal assistance', *Scandinavian Journal of Disability Research*, 19(2), p. 97.

147 Bonfils, I. and Askheim, O. (2014) 'Empowerment and personal assistance – resistance, consumer choice, partnership or discipline?', *Scandinavian Journal of Disability Research* 16(1), p. 73.

148 See, for example, Perspectief (2012) *Violations of human rights of people with disabilities in Netherlands*, available at: <http://www.netwerkperspectief.nl/actueel/2012samenvattingupr.pdf>.

149 BRK – Allianz (n. 37), p. 44.

dential care, they are not given a choice but to opt for the latter. Thus, 'cost ceilings' discriminate against people with the highest support needs and serve as a barrier to their independent living. At the same time, they create financial incentives for the relevant authorities to provide residential care.¹⁵⁰ Other financial incentives for residential care provision can come from the way services are funded. For example, this happens when the funding is tied to residential placements and is not available if the person prefers to live in their own home.¹⁵¹

5.2.3 Structural barriers in the assessment process

There are also structural barriers in the way assessment is organised and conducted that restricts access to services. For example, the assessment process can be too *complicated*, consisting of different assessments and involving many agencies. This can be a barrier for people with intellectual disabilities, but also for less educated and poorer people, for minorities and indigenous populations. Assessment process can also be very stressful and time consuming, interfering with person's other commitments, including work.¹⁵²

Accessibility, which is essential for ensuring that disabled people are able to participate meaningfully in the assessment process, is not always guaranteed. For example, one of the participants in the research shared that the lack of a qualified sign-language interpreter has led to people being institutionalised, because of miscommunication during the assessment process.¹⁵³

The application and assessment process requires a certain *knowledge* of individual rights and entitlements, confidence and assertiveness, which puts in a more favourable position disabled people with good education, coming from relatively well-off families, rather than those with no qualifications or from minority backgrounds.



'It is more difficult to get support for people who are in poverty, do not have a high level of education and they are not able to articulate their demands or know their rights.'¹⁵⁴

In both low- and high-income countries assessment can be very *medicalised*.¹⁵⁵ This means that it focuses on a disabled person's impairment and medical history, rather than on identifying environmental barriers that restrict their participation in society. Since the assessment is key for determining the type and level of support people receive, a medicalised assessment may mean that disabled people's support needs related to inclusion – rather than just basic needs – are not adequately addressed.

Overall, assessment is used by many countries to judge eligibility for services and restrict access, rather than to identify barriers to participation in society. As pointed out by one of the consultation participants: 'The assessment is designed in a way to ensure that the majority of people don't get through.'¹⁵⁶

150 Morris (n. 62), p. 11.

151 Directorate General for Internal Policies (n. 83), p. 24.

152 Article 33 (2015) *Disability rights in Aotearoa New Zealand: participation and poverty*, para. 19, available at: <http://www.dpa.org.nz/convention-coalition-monitoring-reports-2015>.

153 Consultation Europe.

154 Consultation Europe

155 Consultations Europe and Asia and the Pacific.

156 Consultation Europe.

Recommendations

- ▶ A wide range of support services should be made available to allow for the diverse support needs of disabled people to be addressed.¹⁵⁷ The range of community support services should not be limited legally, to allow for flexible and innovative services and arrangements to be introduced.
- ▶ Support services for families should also be provided.
- ▶ In line with the CRPD principles and philosophy, it should be ensured that community supports respect disabled people's dignity and autonomy and promote their full inclusion and participation in society.
 - Disabled people should have choice and control over their support and should be able to make decisions about the type of support they want and who, where, when and how will provide it, based on their preferences. They should be able to choose their preferred degree of control over service provision and not be required to accept a particular support arrangement. Adequate and accessible information and support should be provided to disabled people and their families to allow for real choice.
 - Choice and control is also relevant to children – they should have their views heard and considered when decisions are made on issues affecting them.¹⁵⁸ Their involvement should be based on their best interest and should not be restricted by the type and degree of their impairment.
- ▶ Disabled people should have access to adequate support in the community regardless of their place of residence; for example, whether they live in cities or in rural areas. Measures should be taken to ensure that decentralisation of services does not negatively affect access to support in the community. Disabled people should be able to retain their support, when moving between different regions or countries.
- ▶ Access to support should be granted on the basis of the person's need for assistance. It should not depend on the type or degree of impairment, income, family situation, engagement in specific activities, or other. For example, people living with their (extended) families should be able to use the same type and level of support as people living alone or with friends. People with intellectual and psychosocial disabilities should have access to the same services, available to other disabled people, including personal assistance. Children and older people with disabilities should also have access to personal assistance.
- ▶ Needs assessment should be based on a human rights model of disability, looking to identify the attitudinal and environmental barriers hindering participation.
- ▶ Sustainability of services should be ensured through an adequate regulatory framework and budget allocations.
- ▶ Disabled people and their organisations should be involved in the planning and development of services.

¹⁵⁷ This encompasses 'a wide range of formal and informal interventions, including 'live assistance and intermediaries, mobility aids and assistive devices and technologies. It also includes personal assistance; support in decision-making; communication support, such as sign language interpreters and alternative and augmentative communication; mobility support, such as assistive technology or service animals; living arrangements services for securing housing and household help; and community services. Persons with disabilities may also need support in accessing and using general services, such as health, education and justice.' (Report of the Special Rapporteur on the rights of persons with disabilities (n. 131), para. 14).

¹⁵⁸ United Nations Convention on the Rights of the Child, Article 12.

5.3 Poor quality services

The question about the quality of services is directly linked to the question about how quality is defined and measured. From the perspective of Article 19, two of the key characteristics of high quality services should be related to: 1) the degree of choice and control disabled people have over their support and 2) whether the support provided contributes to inclusion and participation in the community. Most of the services in low- and high-income countries do not currently satisfy these criteria. As the present report shows, choice and control is restricted by abusive and coercive practices in service provision, such as institutionalisation, forced treatment and restriction of legal capacity, discriminatory eligibility criteria and conditionality, 'forced co-tenancy' and bundling of access to services with a particular living arrangement. Disabled people often cannot choose who, where, when and how will provide the assistance. For example, this is the case when service providers are contracted by the state directly, rather than by disabled people, through direct payments or personal budgets.

Quality standard and/or performance indicators have been introduced in many countries as a tool to monitor and assess the quality of services provided. However, in some cases, these standards and indicators fail to measure the outcomes for disabled people; for example, in terms of participation in the community or their access to independent living. They tend to focus on the technical aspects of service provision, such as the size of the space provided, the number of people served, clothing and food or hygiene.¹⁵⁹ Although such criteria may be included, they should not constitute the core of the quality standards. Another issue with standards is that they are often developed without consultation with disabled people, who are also rarely meaningfully involved in the monitoring and evaluation of services. Finally, the monitoring of the quality of services is often restricted to public sector providers; the focus when it comes to private providers is mostly on working conditions.

Recommendations

- ▶ Quality standards for services should be developed with the involvement of disabled people and their organisations. The standards should be based on a human rights understanding of disability and should also look at outcomes for disabled people.
- ▶ Disabled people should also be involved in the monitoring and evaluation of services.
- ▶ Clear and effective complaint procedures and mechanisms need to be established, providing protection to people making complaints and ensuring there is an independent system for processing complaints.¹⁶⁰
- ▶ The quality of services should be judged on the basis of their contribution to inclusion and participation in the community and the degree of choice and control that people using services have over the support. Other important quality principles include: a human rights approach to disability, involvement of disabled people in the design and implementation of services, person-centeredness, and accessibility.

5.4 Inadequate resources

Adequate funding is essential for ensuring there is a range of affordable and accessible support services, that can enable disabled people to live and participate in the community. However, many countries are either not able to allocate adequate resources or have introduced retrogressive austerity measures, cutting funding for disability support.

¹⁵⁹ European Expert Group (n. 46), p. 136.

¹⁶⁰ See European Expert Group (n. 46), p. 145.

5.4.1 Austerity measures

In the aftermath of the financial crisis, a number of austerity measures have been introduced in the affected countries, with a significant negative impact on availability, affordability and accessibility of support for disabled people.¹⁶¹ These measures include cuts in public spending, merging of services, further restrictions of access to services, reductions in direct payments or personal budgets and replacing cash benefits with in-kind benefits. They have led to revival of residential care placements and the application of the medical model, withdrawal of support from disabled persons' organisations, privatisation of services, staff cuts and reductions in staff training.¹⁶²

In some countries, austerity has had a devastating impact on independent living, limiting substantially disabled people's choice and control over the support they use and over their day-to-day lives. For example, one survey conducted in 2015 shows that 30% of the respondents report a reduction of choice and control.¹⁶³ Choice and control are negatively affected by the reduction of the available community support and its quality. This can force disabled people into institutional care and can drive them deeper into poverty and exclusion. Recent reports show that the number of places in residential institutions across Europe is increasing.¹⁶⁴ The quality of life is also affected and in one country, there have been cases reported of people who have committed suicide after being denied support.¹⁶⁵ Thus, austerity measures 'raise important concerns in relation to the States' obligations of non-retrogression, non-discrimination and compliance with minimum core obligations'.¹⁶⁶

5.4.2 Limited resources

The development of community services, especially where state support for disabled people is lacking or is very limited, may require significant investments. At the same time, many low-income countries have very limited resources that can be used to fund support, which can slow down the implementation of the CRPD.

The CRPD recognises that the full realisation of economic, social and cultural rights may not be achieved immediately and allows the states to implement them in a progressive manner, 'to the maximum of their available resources'.¹⁶⁷ However, this should not be used by the States as an excuse not to take any measures. In its General Comment on states' obligations concerning progressive realisation, the Committee on Economic Social and Cultural Rights (CESCR) stresses that:



'even where the available resources are demonstrably inadequate, the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances. Moreover, the obligations to monitor the extent of the realization, or more especially of the nonrealization, of economic, social

161 See, for example, European Foundation Centre (2012) *Assessing the impact of European governments' austerity plans on the rights of people with disabilities*, available at: http://efc.issuelab.org/resource/assessing_the_impact_of_european_governments_austerity_plans_on_the_rights_of_people_with_disabilities; Hande, M. and Kelly, C. (2015) 'Organizing survival and resistance in austere times: shifting disability activism and care politics in Ontario, Canada', *Disability and Society* 30(7), pp. 961–975.

162 European Foundation Centre (n. 159), p. 27.

163 In-control (2015) *Promoting people's right to choice and control under the Care Act 2014*. Available at: [http://www.in-control.org.uk/media/177327/promoting%20choice%20and%20control%20\(final\).pdf](http://www.in-control.org.uk/media/177327/promoting%20choice%20and%20control%20(final).pdf)

164 Directorate General for Internal Policies (n. 83).

165 See, for example, <http://www.disabilitynewsservice.com/coroners-ground-breaking-verdict-suicide-was-triggered-by-fit-for-work-test/>.

166 OHCHR (2013) *Report on Austerity Measures and Economic Social and Cultural Rights*, para. 42, available at: http://www.ohchr.org/Documents/Issues/Development/RightsCrisis/E-2013-82_en.pdf.

167 Article 4

and cultural rights, and to devise strategies and programmes for their promotion, are not in any way eliminated as a result of resource constraints.’¹⁶⁸

The CESCR further notes that:



‘while the full realization of the relevant rights may be achieved progressively, steps towards that goal must be taken within a reasonably short time after the Covenant’s entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the Covenant.’¹⁶⁹

Recommendations

- ▶ Even in the context of limited resources, states should take steps towards the realisation of the right of disabled people to live independently and be included in the community, ‘including by establishing strategies and programmes, with clear targets, benchmarks and time frames’.¹⁷⁰
- ▶ The states should refrain from introducing retrogressive measures involving cuts in services and benefits, restrictions of access to services and other.
- ▶ Where such measures have already been introduced, the States should analyse their impact on the rights of disabled people and take remedial actions, if the protection of their rights is regressing or international law is being infringed.¹⁷¹ It should be ensured that disabled people’s right to live independently is not restricted.
- ▶ Any decision to adopt retrogressive measures will require the States to demonstrate that there has been a ‘careful consideration of all alternatives and they are duly justified by reference 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’.¹⁷² The States should also ensure that the measures are not ‘directly or indirectly discriminatory’, ‘will not have a direct impact on the realization of the rights set out in the Convention; or an unreasonable impact on acquired rights or whether an individual or group will be deprived of access to the minimum level of social security’ and that affected groups have been genuinely involved in ‘examining proposed measures and alternatives’.¹⁷³

168 Committee on Economic Social and Cultural Rights, General Comment 3, The nature of States parties’ obligations (art. 2, para. 1, of the Covenant), para. 11, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCESCR%2fGEC%2f4758&Lang=en.

169 Ibid, para. 2.

170 CRPD Committee (2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention*, para. 44, available at: www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc

171 EU Resolution on the Situation of Fundamental Rights in the EU (2013-2014) – <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2f%2fEP%2f%2fTEXT%2bTA%2bP8-TA-2015-0286%2b0%2bDOC%2bXML%2bV0%2f%2fEN&language=EN>, para. 141

172 CRPD Committee (n. 168), para. 46.

173 Ibid, para. 46.

Chapter 6: Barriers in Mainstream Services and Facilities

Access to mainstream services and facilities is another key element of Article 19. It requires that public services and facilities ‘are available on an equal basis to persons with disabilities and are responsive to their needs’. However, this element is often overlooked. For example, deinstitutionalisation plans tend to focus on closing residential institutions and moving people in the community, without consideration of accessibility of community services and facilities.¹⁷⁴ Countries continue to invest in the development of segregating housing, education and employment, instead of focusing on making services and facilities accessible to all.¹⁷⁵ Disabled people’s access to services and facilities is generally not included in national plans for health, education, transportation and employment.¹⁷⁶

The insufficient attention paid to making community services and facilities accessible hinders disabled people’s full inclusion and participation in society. For example, the lack of accessible and affordable housing limits people’s choices of where and with whom to live to two options – they can ‘choose’ between going to a segregated setting for disabled (or older) people or staying with their family. The lack of accessible transportation and built environment restricts disabled people’s mobility and contributes to their exclusion from other services, such as education and health care. Inaccessible mainstream services also perpetuate a view of disabled people as being of less value, which is another barrier to full inclusion.



‘75% of children with intellectual disabilities are in segregated primary schools and 85% - in segregated secondary schools... This means that the misrecognition of people with intellectual disabilities as equal citizens is institutionalised in the education ... the diminishment of their status as citizen is organised through the educational setting.’¹⁷⁷

The same mechanism operates when it comes to employment and all other areas of life – segregation perpetuates negative attitudes towards disabled people, which then perpetuate segregation.

The poorly prepared and implemented inclusion is another problem, with potentially adverse consequences for disabled people. For example, disabled children can be subjected to bullying and abuse in mainstream schools or receive poor education, if teaching and learning methods are not inclusive, adequate support is not provided and negative attitudes are not addressed. Similarly, the closure of sheltered workshops, without sufficient support to workers and measures to enable employment in the mainstream environment, may lead to disabled people remaining unemployed.¹⁷⁸

The development of accessible mainstream services is often hindered by the lack of a vision of community living and the lack of knowledge about the nature of inclusion and how it can be realised in practice.



‘They [policy-makers] know what is not inclusive education, but do not know what is inclusive education.’¹⁷⁹

174 Consultations Europe.

175 See section Prevalence of institutional services on p. 23.

176 Inclusion international (n. 90), p. 76.

177 Consultation North America.

178 For example, two years after the closure of Remploy factories in the UK, less than half of the people who were looking for other form of employment, have managed to find another job (Response by Mark Harper, 15 October 2014, available at: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-questions-answers/?page=121&-max=20&questiontype=AllQuestions&house=commons%2Clords&use-dates=True&answered-from=2014-09-12&answered-to=2014-10-21>).

179 Consultation MENA.



‘It is not understood what Article 19 is about or what it is that we need to do to for the full realisation of Article 19.’¹⁸⁰

Recommendations

- ▶ Measures to make mainstream services accessible to persons with disabilities should be developed in parallel with other measures¹⁸¹ to support independent living and inclusion in the community.
- ▶ Disability should be mainstreamed; that is, mainstream policies and programmes should take into account the needs of disabled people and include disability-related provisions.
- ▶ A comprehensive policy framework supporting the development of inclusive mainstream services should be introduced, with a clear timeframe, benchmarks and budget and sanctions in cases of violations. Monitoring mechanisms should ensure the implementation of the framework.
- ▶ Inter-sectoral and inter-ministerial coordination should be ensured.
- ▶ Legislation should be reviewed to ensure that it does not discriminate against persons with disabilities and is not contrary to the CRPD. Together with this, a requirement for all mainstream services to be made accessible for all citizens should be incorporated in legislation.
- ▶ Individualised support and reasonable accommodation should be provided to disabled people to enable their access to mainstream services and facilities.

¹⁸⁰ Consultation Africa.

¹⁸¹ For example, development of support services in community for disabled people and their families, awareness raising campaigns, anti-discrimination legislation and measures, social protection, etc.

Chapter 7: Barriers to other CRPD rights that impact on independent living

The right to live independently and be included in the community is closely linked to other rights, set out in the CRPD. It cannot be fulfilled without ensuring, for example, the right of disabled people to non-discrimination (Article 5), accessibility (Article 9), equal recognition before the law (Article 12), access to justice (Article 13), liberty and security (Article 14), freedom from torture and from exploitation, violence and abuse (Articles 15 and 16), liberty of movement and nationality (Article 18), personal mobility (Article 20), expression of opinion and access to information, respect for privacy and for the family (Articles 22 and 23) education, health, habilitation and rehabilitation, work and employment, and social protection (Articles 24-28), participation in political and public life and in cultural life, recreation and sports (Articles 29 and 30). It also cannot be fulfilled without awareness raising activities, without specific measures to ensure full enjoyment of disabled women and children of all human rights, and without consulting and involving disabled people in all decision-making processes concerning issues related to people with disabilities (Article 4 (3)).

At present, however, there are various barriers to the realisation of these rights, undermining disabled people's enjoyment of the right to live independently and be included in the community. Listed below are examples of barriers related to poverty and social protection, substitute decision-making, multiple discrimination, education, employment, participation and data collection. Negative attitudes and stigma, requiring awareness-raising measures, were discussed in Chapter 2.

7.1 Poverty and disability-specific costs

Article 28 recognises the right of disabled people to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions. Despite this, disabled people, as a group, continue to be among the poorest in the world and they experience higher rates of poverty and deprivation and lower level of income than the general population.¹⁸² This affects disabled people in both low- and high-income countries. A key factor for the higher poverty levels is disabled people's exclusion from the labour market, due to a combination of environmental and attitudinal barriers and impairment. Another factor is the additional disability-related costs disabled people incur, such as personal assistance, mobility aids, transportation and other. Many of these extra costs are caused by the inaccessible environment. For example, the lack of accessible public transportation can require private accessible vehicles to be hired at a higher cost. As highlighted by Morris, 'The combination of these two factors creates a vicious circle of disadvantage. Reduced employment opportunities mean that disabled people are *less likely* to have sufficient resources to meet the additional support needs, which they are *more likely* to experience than non-disabled people.'¹⁸³

The inability to cover additional disability-related costs makes mainstream services unaffordable for disabled people. For example, some disabled people may need a wheelchair to go to school or work and when they cannot afford to buy one, they are unable to take up education or employment.¹⁸⁴ Others may need sign-language interpretation, personal assistance, a support person or specific software, in order to have the same opportunities as non-disabled people, but they may not be able to afford these due to their high cost. This pushes disabled people further into poverty and prevents them from climbing out of poverty. It can also be a barrier to their inclusion in society. As the Special Rapporteur on the Rights of Persons

182 Report of the Special Rapporteur on the rights of persons with disabilities (n. 136), para. 25.

183 Morris (n. 62), p. 48.

184 Consultation Africa.

with Disabilities pointed out, ‘the burden of disability-related extra costs can easily nullify the enjoyment of other human rights, including living independently and with freedom of choice in any given society’.¹⁸⁵

7.2 Substitute decision-making

Article 12 provides that disabled people are entitled to legal capacity on an equal basis with others in all aspects of life. Legal capacity refers to both the ability to hold rights and duties and to exercise those rights and duties, that is, ‘to act on those rights and to have those actions recognised by the law’.¹⁸⁶

In both high and low-income countries, however, many disabled people, usually people with intellectual and psychosocial disabilities, are denied the right to make their own decisions.¹⁸⁷ This can be done formally, through guardianship orders, which restrict disabled person’s legal capacity and appoint a guardian to act on their behalf. It can also be done informally – through established family and community practices, without going through the court process.



‘What I eat is decided by the family, where I live, what I wear, whether to visit my friends or not, which school I go to.’¹⁸⁸

The system of substitute decision-making, formal or informal, is a key barrier to independent living and inclusion in community. For example, it restricts or denies disabled people’s right to choose where and with whom to live. There is also a close link between guardianship and institutionalisation.¹⁸⁹ Many disabled people are placed in institutions against their will by formal or informal guardians – ‘There are still a number of legal provisions which allow almost anyone in society to kind of refer a disabled person [to an institution] and put them away’.¹⁹⁰

The right to legal capacity and the right to live in the community are interconnected. Without recognising disabled people’s right to make decisions, full inclusion in the community is impossible, and vice versa – support in the community (for example, supported decision-making arrangements) is essential for strengthening the exercise of legal capacity.

7.3 Cross-cutting issues

Some disabled people face more complex barriers to the realisation of their right to live independently in the community, due to their belonging to more than one social group. The CRPD recognises that ‘person’s race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status’¹⁹¹ can pose additional challenges to disabled people.

For example, **disabled women** across the world ‘are multiply disadvantaged, facing significant difficulties in obtaining access to adequate housing, healthcare, public transport, education, vocational training and

185 Report of the Special Rapporteur on the rights of persons with disabilities (n. 136), para. 32.

186 Committee on the Rights of Persons with Disabilities (2014), General Comment No. 1 (2014), Article 12: Equal recognition before the law, para. 14, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbol-no=CRPD/C/GC/1&Lang=en

187 Inclusion international (n. 90), p. 56.

188 Consultation Africa.

189 See, for example, Mental Health Europe and Mental Health Initiative of the Open Society Foundation (2012) *Mapping Exclusion - Institutional and community-based services in the mental health field in Europe*, available at: www.mhe-sme.org/policy/mapping-exclusion/ and Directorate General for Internal Policies (n. 83), p. 22.

190 Consultation Asia and the Pacific.

191 Preamble, (p)

employment, experiencing inequality in access to credit and other productive resources, and rarely participating in decision-making processes'.¹⁹² Furthermore, their access to services can be additionally restricted by patriarchal cultural norms, for example, requiring women to request permission to go out and to be accompanied when outside their homes.¹⁹³

Older people are generally perceived as less able to contribute to society and therefore their support is predominantly organised in some form of residential care. Older disabled people can thus find it more difficult to access individualised support in community, which is 'reserved' for people who are still able to work and contribute to the society.¹⁹⁴ They are also 'routinely denied access to resources and services', such as health, decent work and livelihood opportunities.¹⁹⁵

Disabled **children** are generally overrepresented in segregating residential institutions and even where institutionalisation of children under a certain age is banned, exceptions for disabled children are often allowed.¹⁹⁶ Young people in many countries 'lack appropriate services, opportunities and voice'.¹⁹⁷

Indigenous people and **ethnic minorities** often find it more difficult to access support, due to their geographical isolation, cultural differences, and diminished social status. Support needs of disabled asylum seekers, migrants and refugees often remain unidentified, due to problems with the humanitarian response on the ground, including the lack of formal procedures for identification and adequately prepared staff.¹⁹⁸ Conditions for access to social protection for disabled migrants can be discriminatory, requiring them to wait longer than other migrants before being allowed to access support.¹⁹⁹

7.4 Lack of equal access to education and employment

The right to live independently and be included in the community can be restricted by the lack of access to quality education in a mainstream setting and to equal employment opportunities. Inclusive education is one of the pillars of independent living – 'without access to education, access to employment and consequently independent living become nearly impossible'.²⁰⁰ However, at present '[m]any millions of persons with disabilities continue to be denied a right to education, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision'.²⁰¹

192 European Parliament Resolution of 11 December 2013 on Women with Disabilities (2013/2065/INI), B, available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52013IP0579>. See also: *International norms and standards relating to disability*, part V. Rights of special groups with disabilities, available at: <http://www.un.org/esa/socdev/enable/comp504.htm#4.1>

193 Consultations MENA.

194 For example, ENIL surveys of personal assistance services in Europe, held in 2013 and 2015, has found that some countries exclude people above 65 from access to the service. See: <http://enil.eu/policy/personal-assistance-tables/?s=personal+assistance+survey#>

195 United Nations Development Group (2013) *Global Thematic Consultation on Addressing Inequalities in the Post-2015 Development Agenda*, p. 47, available at: http://www.unescobkk.org/fileadmin/user_upload/appeal/MLE/Synthesis_Report_on_the_Global_Thematic_Consultation_on_Addressing_Inequalities.pdf.

196 Consultations North America. See also European Disability Forum (2014) *Alternative report to the UN Committee on the Rights of Persons with Disabilities*, p. 36, available at: <http://www.edf-feph.org/what-does-edf-do-what-edf-alternative-report>.

197 United Nations Development Group (n. 193), p. 46.

198 See, for example, European Union Agency for Fundamental Rights (n.d.) *Thematic focus: migrants with disabilities*, available at <http://fra.europa.eu/en/theme/asylum-migration-borders/overviews/focus-disability> and Arab Forum for the Rights of Persons with Disabilities (2016) *Disability inclusion among refugees in the Middle East and North Africa*, available at: <http://www.disabledpeoplesinternational.org/documents/DPO-Report-FINAL.pdf>.

199 Disability representative, advocacy and human rights organisations (n. 93), para. 522.

200 ENIL (2015) *ENIL's Written contribution to the Day of General Discussion on the right to education for persons with disabilities*, available at: http://enil.eu/wp-content/uploads/2015/03/Contribution_DGDEducation_200315_fin.docx.

201 Committee on the Rights of Persons with Disabilities (2016) General comment No 4 (2016) on the right to inclusive education, para. 3, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD/C/GC/4&Lang=en.

Exclusion from the labour market, as pointed out earlier, is another huge barrier to independent living, as it has a strong impact on disabled people's income and access to goods and services. Currently, unemployment rates of disabled people across the world are generally higher than those of non-disabled people, reaching up to 100% per cent in some countries.²⁰² Even when in employment, disabled people often receive lower wages than non-disabled people, as a result of discrimination.²⁰³

7.5 Participation

Genuine participation of disabled people in the development and implementation of disability-related policies is essential for ensuring that policies reflect their needs and interests. The CRPD requires States to 'closely consult with and actively involve' disabled people – children as well as adults – in decision-making on issues related to disabilities, including the development and implementation of legislation and policy to implement the Convention.²⁰⁴ It also provides that disabled people and their representative organisations 'shall be involved and participate fully' in monitoring the implementation of the Convention.²⁰⁵

In reality, however, participation of disabled people and their representative organisations is often lacking or inadequate.²⁰⁶ In some cases, there are no mechanisms adopted to ensure systemic participation.²⁰⁷ In other cases, even when disabled people are involved, this is done in a tokenistic way – to demonstrate involvement but without a real impact on the issues discussed.²⁰⁸ As described in one of the alternative reports to the CRPD Committee '[d]e jure, organizations of people with disabilities may be involved to the development of legislation, policies, but de facto, in most cases such involvement is a formality.'²⁰⁹ A barrier to meaningful participation can also be the lack of independence from the state, of disabled people's organisation or the relevant consultative body, of which they are part.²¹⁰ In this case, participation can have instrumental function – to sustain, rather than challenge, the status quo.

7.6 Lack of data

Article 31 of the CRPD requires states to collect data 'to enable them to formulate and implement policies to give effect to the present Convention'. Such data should be 'disaggregated, as appropriate, and used to help assess the implementation' of the CRPD and 'to identify and address the barriers faced by persons with disabilities'. As highlighted by a major report into the process of deinstitutionalisation in Europe²¹¹, 'comprehensive information is not available for all types of residential services provided nor for all the client groups involved, nor is there clarity about the definition of kinds and characteristics of services provided or people served. Where such information exists, it is not always collected at the national level.'

202 See, for example, Backup, S. (2009) *The price of exclusion: the economic consequences of excluding people with disabilities from the world of work*, Employment Working Paper No 43, Geneva: International Labour Organisation, p. 45, available at: http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_119305.pdf.

203 World Health Organisation and the World Bank (n. 58), p. 237.

204 Article 4 (3).

205 Article 33 (3).

206 See, for example, CRPD Committee Concluding observations on Guatemala, Lithuania, Slovakia, Uganda, Denmark, and Ecuador, available at: http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD

207 See, for example, CRPD Committee Concluding observations on Ethiopia and China, available at: http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD

208 See, for example, The response to the List of Issues on Ukraine, p.3.

209 Ibid, p. 29.

210 See Mladenov, T. (2009) 'Institutional woes of participation: Bulgarian disabled people's organisations and policy-making, in *Disability and Society* 24(1): 33-45.

211 See Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent, p. 94. (further referred to as the 'DECLOC Report')

This is a barrier to the implementation of Article 19, as it does not allow the monitoring of progress, and enables countries to evade scrutiny over the number of people in institutional care.

Recommendations

► Social protection

- In line with Article 28, disabled people should be provided with access to social protection programmes and services. This includes measures to facilitate access to appropriate and affordable services, devices or other disability-related assistance, to public housing, retirement benefits and programmes, and support with disability-related costs²¹².
- Disability benefits should not be bundled with support, aimed to reduce poverty, as this may lead to disabled people losing essential disability support without having a sufficient and stable income from employment to cover disability-related expenses.²¹³
- Disability benefits should be provided in a way that ensures that disabled people have choice and control.

► Supported decision-making

- The CRPD Committee states that all forms of substitute decision-making should be abolished and replaced by supported decision-making arrangements, recognizing disabled people's right to make their own decisions.²¹⁴
- Support in the community should be provided to enable disabled people to exercise their legal capacity and to make decisions that have legal effect. It should be 'available at nominal or no cost to persons with disabilities' to ensure that 'lack of financial resources is not a barrier to accessing support in the exercise of legal capacity'.²¹⁵
- Accessible information about supported decision-making arrangements should be provided to disabled people and their families.

► Cross-cutting issues

- Community support should take into account the specific disadvantages that certain disabled people face and seek to remove the additional barriers restricting their choice and access to support and mainstream services. For example, assistance should be gender and age-sensitive.²¹⁶

► Access to employment and education

- Legislation should be amended to ensure that it does not create barriers to education and employment.
- Public services, such as education and employment, should include provision of additional support, to ensure full inclusion of disabled people.

► Participation

- In line with Article 4(3), disabled people should be actively involved in policy-making and development of legislation, including related to the implementation of the CRPD. For example, they should be consulted in the assessment of the situation and identifying the barriers to the implementation of Article 19 and the measures to address them.

212 See UN CRPD, Article 28.

213 For further guidance with regard to social protection, see the Report of the Special Rapporteur on the Rights of Persons with Disabilities (n. 137), para. 52-54.

214 For further guidance, see Article 12 CRPD and Committee on the Rights of Persons with Disabilities (n. 184).

215 Committee on the Rights of Persons with Disabilities (n. 185), 29(e).

216 Report of the Special Rapporteur on the Rights of Persons with Disabilities (n. 131), para. 87.

- Mechanisms should be established to ensure systematic involvement of disabled people and their organisations, rather than ad hoc consultations.
- Measures should be taken to ensure that disabled people can participate meaningfully, by taking into account their accessibility requirements. This may involve, for example, providing information in accessible format, allowing enough time for reflection before and during meetings, ensuring physical accessibility, and providing translation or other support during the meeting. Children should also be enabled to take part.
- Disabled people's organisations should be provided with 'efficient budgetary support'²¹⁷ to participate effectively.

► Data collection

- In line with Article 31, countries should collect disaggregated information at the national level that will enable the CRPD Committee to review progress towards the right to independent living.
- The data collected is likely to 'require a combination of information about numbers of places in services [...] with information about people' living in the community, and the support they receive; it 'needs to include sufficient information about the people served (gender, ethnicity, primary disability) to enable States to ensure that everyone is benefiting from the transition away from institutions to better alternatives in the community'.²¹⁸
- Data relating to the implementation of Article 19 should be available to disabled people and their organisations, as well as to the general public.

²¹⁷ CRPD Committee Concluding observations on Serbia, para. 68, available at: http://tbinternet.ohchr.org/_layouts/Treaty-BodyExternal/SessionsList.aspx?Treaty=CRPD

²¹⁸ DECLOC Report (n. 209), p. 95.

Conclusion

This report has outlined some of the main barriers that hinder the realisation of disabled people's right to live independently and be included in the community. While there are important regional and cross-country differences, related to culture, religion, economic, social and political development, there are also many common challenges. They include the dominance of the medical model of disability and a lack of understanding of the human-rights approach to disability, negative societal attitudes and stereotypes, devaluation of disabled people, inadequate level and quality of support in the community, and inaccessible mainstream services.

To address these challenges, it is important to first ensure that all stakeholders (at national, regional and local level) have a shared understanding of Article 19, which is in line with the philosophy and the main principles of the CRPD, namely individual autonomy and the freedom to make own choices, independence and full and effective inclusion in society. Specific measures to address the various barriers to independent living and inclusion should be adopted and implemented. Disabled people and their organisations should be actively and meaningfully involved in this process and their views should be taken into account. Article 19 may not become a reality overnight, but keeping it on the agenda and taking systematic steps towards its realisation can help ensure that we are getting closer to realising the CRPD vision of disabled people as equal citizens.

Annex 1 – Independent Living Definitions²¹⁹

Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.

Personal Assistance is a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

Community-based services: The development of community-based services requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, health care and other services and support, available and accessible to disabled people in mainstream settings. Disabled people must be able to access mainstream services and opportunities and live as equal citizens. Community-based services should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, the need for special transport because mainstream transport is inaccessible and so on. In many cases, group homes do not support independent living (see Annex 2 below). Where they are provided, they must form part of a range of community-based services that offer genuine, adequately funded independent living options.

219 Adopted in November 2012 by the ENIL board. The definition of independent living was adopted by the European Disability Forum in March 2016.

Annex 2 – Frequently asked questions

Question 1: Can disabled people choose to live in an institution?

Often the decision to live in an institution is not a matter of individual preferences, but a consequence of the lack of options to choose from. When people do not have a place to live, or the institution is the only place they can get support from, they are forced to ‘choose’ to live in an institution.



‘In my country, we asked persons with disabilities living in institutions if they would want to return to their homes in their communities. Many of them said no. I said why? They said because the support services are within the institutions [...]’²²⁰

People may also ‘choose’ institutional settings because they are used to them – they have spent a significant part of their life in an institution and may find it difficult to imagine a different life. Sometimes, they may not have the confidence and the skills to make decisions for themselves, as they have never been allowed to do so. People’s vision and choices can also be limited by negative community attitudes and beliefs²²¹ or by the lack of information about other options.

It is impossible to claim that some disabled people choose to live in an institution, as if they were on a level playing field with others. Disabled people can have a genuine choice only in a truly inclusive and accessible community, with a range of adequate and quality support options, including from peers.

Question 2: Are group homes in line with Article 19?

There are numerous problems with relying on group homes as the preferred form of living arrangement for disabled people. Apart from the institutional character of many such settings²²², a key problem with group homes is that they require disabled people to leave their families and communities and to live with people they often do not know, depriving them of a genuine choice where and with whom to live. For those moving from large institutional facilities, group homes may represent a step towards living in the community, but one where their choices and freedoms continue to be restricted.

Disabled people may choose to live together with other disabled people, and if that is the case, they should be supported to do so. However:

- 3) this should be their choice. This means that there should be a range of genuine independent living options in the community, to allow for real choice. Adequate information and support, including from peers, should also be provided to assist with decision-making.
- 4) the place they live should resemble a home. This requires that:

²²⁰ Consultation Africa.

²²¹ Inclusion international (2012) *Inclusive communities = stronger communities. Global report on Article 19: The right to live independently and be included in the community*, p. 66, available at: <http://inclusion-international.org/wp-content/uploads/2013/07/Global-Report-Living-Colour-dr2-2.pdf>

²²² See section ‘Prevalence of segregating services’, sections ‘Contemporary institutions’ and ‘Re-institutionalisation – when de-institutionalisation goes wrong’.

- the number of people living together is not higher than usual. For example, if most apartments or houses accommodate 4 – 6 people, the same should apply when it comes to disabled people wishing to live together.
- the provision of support and housing is separated, to allow for greater flexibility. Thus, if someone is unhappy about the services they receive, they might decide to change the service provider and continue to live in the same place with the same people.
- there is no block treatment – provision of services is personalised and depends on individual needs and preferences. Block treatment, where all people living in a certain place receive the same services, is one of the key characteristics of institutional culture.
- people can make choices about their daily lives – for example, when to get up and go to bed, what to eat, whether to go out and when, whether to have friends over etc.
- individual privacy is respected and people have personal space and belongings.
- mainstream services and facilities in the area are accessible, so that disabled people are able to use the local transport options, go to work, see the local doctor, use the local hairdresser, access cultural and sports facilities etc.

Question 3: In the context of lacking support services and limited funding – where to start?

When planning the development of services in countries with limited or no community support, it is important to ensure that:

- There is a good understanding of the CRPD philosophy and the Article 3 principles, including respect for inherent dignity, the freedom to make one's own choices, independence and full and effective participation and inclusion in society. It should also be understood that the CRPD covers all disabled people, which means that all disabled people can live independently and be included in the community. Such an understanding will help ensure that the planned measures are in line with the CRPD and do not reproduce segregation and exclusion.
- The local specificities are taken into account. Services that are being developed should respect the cultural norms, while at the same time providing disabled people with choice and control over their assistance, supporting their inclusion in the community.
- Other barriers hindering inclusion, such as attitudes, accessibility, discrimination are also considered.

The planned measures should:

- seek to provide access to individualised support for disabled people (e.g. personal assistance, supported decision-making, counselling, sign-language interpreters) and to technical aids and assistive devices. Together with this, support should be provided to families. It should be possible to combine informal and formal support.
- include awareness raising activities, aimed at building the capacity of key stakeholders (politicians, professionals, media, disabled people and their organisations, families and communities), as well as legal reforms.
- not be limited to supporting disabled people with their basic needs, but should seek to support their active participation in community.

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL has Participatory Status with the Council of Europe, a Consultative Status with ECOSOC and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

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